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ABSTRACT

Ten papers are presented from a 1979 conference on services for families of developmentally disabled persons. R. Bruininks ("The Needs of Families") addresses aspects of direct and support services to families. "Social and Psychological Factors in Family Care" by C. Horejsi suggests that a family's or individual's ability to deal successfully with a disabled member is a function of their motivation, capacity, and environmental opportunities. B. Farber ("Sociological Ambivalence and Family Care") addresses the social contradictions facing parents of developmentally disabled children. W. Roth ("An Economic Model of Social and Psychological Factors in Families with Developmentally Disabled Children") discusses policy options for families: making the handicapped child a better investment or providing family subsidies. In "Economic Factors in Child Care," E. Boggs summarizes benefits of such strategies as early crisis intervention, day care, and respite care. Macro issues of resource allocation and competition are analyzed along with micro issues by R. Moroney ("Allocation of Resources for Family Care"). H. Trapper lists "Barriers to a Family Subsidy Program," including the belief that paying parents to care for their child is wrong. S. Zimmerman reviews current practices and their planning implications in "Families of the Developmentally Disabled: Implications for Research and the Planning and Provision of Services." G. Krantz summarizes conference proceedings and the participants' analysis of relevant public policy options. One of three appendixes briefly describes 21 innovative programs for families. (CL)

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Family Care of Developmentally Disabled Members: Conference Proceedings

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Robert H. Bruininks, Ph.D.
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In planning the conference we were given valuable advice from a number of people who are knowledgeable about the needs of developmentally disabled people and their families. In addition to those whose participation is evident in the authorship of the contents of these Proceedings, advice was formally solicited and received from Ms. Cristy Boswell, Dr. Jack Cockshott, Mr. Allen Cohen, Dr. Eunice Davis, Ms. Joni Fritz, Ms. Doris Haar, Dr. Laird Heal, Mr. Fred Krause, Ms. Toni Lippert, Mr. Gene Patterson, Mr. Robert Perske, Dr. David Rosen, Dr. Richard Scheerenberger, Ms. Joan Van Norstrand, Dr. Luke Watson, Mr. Michael Weber, and Dr. Edward Zigler.

A special note of appreciation is due to Ms. Sheila (Kingston) Pederson and Ms. Jane Clumpner, graduate assistants who participated throughout the preparation for and conduct of the conference.

Finally, the success of the conference depended ultimately upon the presenters whose work comprises the bulk of these Proceedings, and upon the participation of those who attended the conference and who are listed in Appendix C.

Robert H. Bruininks and
Gordon C. Krantz,
Editors
Minneapolis, 1979

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ABOUT THE AUTHORS

The names of all who attended the conference will be found in Appendix C, with the nature of their participation footnoted. The major presenters, whose presentations are printed here, and the writers of the other chapters of these Proceedings are briefly introduced below in the order in which their works appear.

DR. ROBERT H. BRUININKS is Professor of Special Education and Chairman of the Department of Psychoeducational Studies at the University of Minnesota. In addition to teaching and research activities at the University, he served for two years as Director of the Minnesota Developmental Disabilities Office. Dr. Bruininks has consulted widely in the field of special education and its administration. He has published extensively on the subjects of motor development, learning problems and mental retardation, the measurement of psycholinguistic and motor abilities, personnel preparation, and service strategies. He is Director of the project which conducted this conference.

DR. CHARLES HOREJSI is a professor of social work at the University of Montana. His professional experience has been in the areas of marriage and family counseling, mental health and juvenile corrections. He has published in areas of developmental disabilities, rural social service delivery, sex education and social work education. His book, *Foster Family Care* (Charles C. Thomas) will be available in 1979.

DR. BERNARD FARBER is a professor of sociology at Arizona State University. He received his Ph.D. degree at the University of Chicago in 1953. Since then, his major research interests have been in mental retardation and in the sociology of the family and kinship. He has written a book, *Mental Retardation: Its Social Context and Social Consequences* (1968), as well as monographs on effects of retarded children on family relationships (in the *Society for Research in Child Development* and in the *Council of Exceptional Children* series). His other writings include several books on family and kinship organization.

DR. WILLIAM ROTH is at the School of Social Welfare at the State University of New York at Albany. He was Research Associate at the Institute for Research on Poverty at the University of Wisconsin and before that performed research for the Carnegie Council on Children. He is co-author with John Gliedman of *Handicapped Children in America*, forthcoming shortly from Harcourt, Brace, Jovanovich. This book analyzes the social, economic and political situation of handicapped children. Dr. Roth received his B.A. from Yale University in Politics, Economics and Mathematics and his Ph.D. from the University of California at Berkeley in Political Science. His current work largely concerns questions of disability.

DR. ELIZABETH M. BOGGS is a long time advocate for the mentally retarded, to whose interests her attention was called when her son, born in 1945, was identified as multiply handicapped. She has experience in family care. Additionally, she has worked in the areas of public policy and legislation at the state level in New Jersey and Pennsylvania, and particularly at the federal level. She was a founding member of NARC, has worked in seminars and task forces of the International League of Societies for the Mentally Handicapped, and in 1971 won the Kennedy International Award for Leadership in Mental Retardation. Although the professional field for which she prepared was mathematical chemistry, her work in mental retardation has been recognized by professional societies; she is a Fellow of AAMD, and an Honorary Fellow of the American Psychiatric Association and of the American Academy of Pediatrics.

DR. ROBERT MORONEY is Professor of Social Planning in the Department of City and Regional Planning at the University of North Carolina. He has graduate degrees in social work (MSW), public health (MPH), and Social Welfare Planning (Ph.D.). While a Visiting Fellow at the Centre for Studies in Social Policy in London, he conducted an inquiry into social policies as they affect families. He has published extensively in the areas of service delivery, social planning, needs assessment and program evaluation, family policy and the handicapped, and management information systems.

In addition to teaching and research, Dr. Moroney has worked as a counselor and as a community organizer.

DR. HAROLD TAPPER is a specialist in the management of human services and has had experience in a variety of direct service settings—including special education, work training, and residential settings—and in supportive services, including consumer and provider advocacy agencies, and state and national planning agencies. He has conducted and published research in the areas of individualized program planning, national policy analysis, and the organization of human services.

He is presently employed as the executive director of the Association of Residences for the Retarded in Minnesota.

DR. SHIRLEY ZIMMERMAN is Assistant Professor and Assistant Director of Continuing Education in Social Work at the University of Minnesota. Dr. Zimmerman is a former post-doctorate fellow in the Family Impact Analysis Training Program of the Family Study Center, University of Minnesota. She is the author of several articles on family policy. Among these are: "The Family and Its Relevance for Social Policy" (*Social Casework*, November, 1976), and "Reassessing the Impact of Public Policy on Family Functioning," (*Social Casework*, October, 1978). This past year she co-directed and co-authored a report on "Legislator's Attitudes toward Family Policy: A Report of a Survey," Minnesota Family Study Center, Family Impact Series, No. 13.

DR. GORDON C. KRANTZ is a counseling psychologist with experience in vocational rehabilitation, special education, vocational education, and social welfare of the mentally retarded. His MA is in psychology and his Ph.D. is in educational administration. He has conducted and published research in the areas of vocational behaviors, program and service system design, vocational evaluation and work adjustment, and the demographics of handicap and service. He is employed as research scientist by the Project on Deinstitutionalization, and coordinated this conference.

THE NEEDS OF FAMILIES

Robert H. Bruininks

University of Minnesota

Nearly everyone in society is a part of some family unit, a formally developed entity found in all known societies that assumes responsibility for the care of its members and the transmission of the important norms of a larger culture (Goode, 1964). The fact that most persons in our society, particularly during the period of birth to maturity, live in family units is no less true for developmentally disabled people. Recent surveys of publicly operated and other out-of-home residential placements for mentally retarded people (Developmental Disabilities Project on Residential Services and Community Adjustment, 1978; Krantz, Bruininks & Clumpner, 1978; Scheerenberger, 1978) indicate that approximately 215,000 mentally retarded people live in publicly operated residential facilities and other licensed residential living arrangements. Even assuming that several thousand additional persons live in foster care arrangements and non-licensed out-of-home placements, it seems quite safe to assume that only a small percentage of mentally retarded people live outside their natural homes during the developmental period of life. This conclusion can be safely applied to persons with other developmental disabilities as well, since there is a dearth of available residential placements for severely handicapped people who are not defined by social agencies as mentally retarded.

Given the fact that most developmentally disabled people spend much of their lives with members of their natural family or in other environments that can be characterized as family care settings,* it is surprising that so little attention has been given by units of government, agencies and researchers to the needs of natural and surrogate families with developmentally disabled members. Most of the literature in this area is comprised of eloquent statements by parents. Except for the work of a few researchers (cf., Farber, 1968), however, there is little in the published literature regarding the social, economic or programmatic issues involved in providing care and opportunities for developmentally disabled people in family care settings. The limited research findings and devel-

*In one of the conference sessions, Dr. Elizabeth Boggs recommended that the concept of family care include care in the natural parental family, sibling family, adoptive family (long-term), and foster family (ordinarily a residence and family structure with no more than three fostered members). Although most of the discussion at the conference concerned the needs of natural families with developmentally disabled members, the definition recommended by Dr. Boggs has considerable heuristic value in considering issues addressed at the conference and in this volume.

opment of ideas in this area is paralleled by inadequate attention given by government programs and service agencies to the needs of families and other persons who provide family care for developmentally disabled persons.

Surveys on the Needs of Families

Although the service needs of families with developmentally disabled members is a relatively neglected area of interest among researchers, there are a few studies and surveys that deserve mention in considering issues involved in family care. In a six state survey of 28 issues and services required to achieve the goal of deinstitutionalization and effective community services, Bruininks Williams and Morreau (1979) found that parents, policy makers and agency personnel indicated that family related services were both low in availability and quality. Nearly all respondents indicated that incentives for care in the family home of a developmentally disabled person and respite care were not available or poor in quality. Furthermore, most of the respondents indicated a need for technical assistance in these areas. Interestingly, respondents to the survey felt that leisure, recreation, employment, and transportation services were particularly inadequate in availability and quality.

Similar findings were recently reported by Dunlap and Hollinsworth (1977) in a survey of approximately 400 families in Alabama. Although a majority of these families did not believe the disabled person had a negative effect on other family members, they did indicate quite strongly the need for assistance. In discussing their results, Dunlop and Hollinsworth noted:

The findings also revealed that when the handicapped person was seen as having affected the family it was more often in areas such as trips, vacations, visiting, shopping, or going to movies or to church, or whether the mother will work. The results also showed that time demands, physical demands, and money problems were more often indicated as important. Extra expenses were important for the respondents who indicated that there had been an effect on the family. Convulsions and seizures, and crippling also were significant factors (p. 292).

The types of services parents would need in order to keep a developmentally disabled child at home were asked of parents in a Minnesota Department of Welfare survey (Minnesota State Planning Agency, 1975). The results indicated the following priorities listed in order of importance:

—Medical (professional availability and funds)
—Supplemental income
—Home assistance
—Special school programs
—Respite care
—Social activities for the child
—Transportation for the child

—Home tutors
—Parent guidance
—Day activity centers

The picture presented by these studies is that families often need assistance through the availability of community services and through provision of relief services. One means of conceptualizing the service needs of developmentally disabled people is through the service framework of the Developmental Disabilities Act (Public Law 94-103), in which services may be divided into "direct service" and "support service" categories (see Table 1).

Table 1
Services Needed to Support Families

DIRECT SERVICE CATEGORIES

Residential Services	**Day Activities Programs**	**Employment Services**
Domiciliary care	Preschool day care	Sheltered employment
Special living arrangements	Preschool education and training	Regular employment
	School-age day care	
	School-age education	
	School-age training	
	Adult day care	
	Adult education and training	

SUPPORT SERVICE CATEGORIES

Identification Services	**Case Management Services**	**Treatment Services**	**Family/Program Support Services**
Diagnosis	Counseling	Medical	Transportation
Evaluation	Protective	Dental	Personal care
Information & referral	Socio-legal	Special	Recreation
	Follow-along		

Reasons for Out-of-Home Placement*

One means of examining the needs of families with developmentally disabled members is by examining the few studies on reasons for the placement of mentally retarded people in residential facilities outside the home. The reasons given in studies for the placement of mentally retarded people in residential facilities appear in Table 2. Problems in the management of the mentally retarded person, family problems, and characteristics of the mentally retarded person

*Much of this material is taken from a report on factors related to admission and readmission of mentally retarded people to residential facilities, prepared by Thorsheim and Bruininks (1978). Again, it is important to note that this material is based upon research with families with mentally retarded members, although it is likely that many of the same issues are present in those families whose developmentally disabled members are not defined as mentally retarded.

have emerged as primary reasons for first admission to residential facilities. Conflict with parents, need for social control, and delinquent behavior create important management problems for the family and community. Family problems caused by the impact of the mentally retarded child on the family may include physical and psychological burdens on parents, child neglect, and additional problems which interfere with family life. Mentally retarded people who are unemployed, homeless, and who lack significant social or work activities or who have physical or psychiatric handicaps are often found among the first admissions to residential facilities. It is evident that many of those factors are highly related to the setting of the mentally retarded persons within the family and the community.

Saenger (1960) found that behavior problems in the community, in combination with "inadequate parents," comprised the single most important factor, after level of retardation, leading to institutionalization. ("Parental inadequacy" was based on interviewer ratings and agency records of the parents' gross emotional stability.) Parents who were irresponsible and incompetent were found twice as frequently among the families of mentally retarded people who had been institutionalized, as compared with families of mentally retarded people remaining in their own homes. While institutions were utilized more frequently for the most severely retarded, behavior problems outside the home were especially important reasons for placement in a residential facility for those with an IQ of 50 or above. For those mentally retarded people with an IQ below 50, problems were more likely to be at home rather than in the community.

Although Saenger drew no conclusions as to which problems required placement in a residential facility and which ones would be tolerated in the community, he did conclude that expanded resources in the community would be helpful to mentally retarded people and their families, whether the mentally retarded family member lived at home or in a residential facility. Expanded community resources were not explicitly outlined by Saenger, but seven areas of major concern were identified by the parents as urgent needs which could have been at least partially met by improved community services.

Farber (1968) summarizes and integrates Saenger's New York findings with the results of his study (Farber, Jenne & Tiege, 1960) conducted in Illinois:

Taken together, the Illinois and the New York City studies indicate that mental retardation alone is not a sufficient explanation for institutionalization. The mentally retarded individual must present some additional problems to either the family or the community which designate him as superfluous or threatening to social relationships (Farber, 1968, p. 197).

In-Home Family Care*

One major reason for urging a family to care for its developmentally disabled member is that a child's development at home is generally superior to a child's development in other placements. (Poznanski,

1973). As noted by Schield (1976), "The home is usually the prime training ground for the development of socially desirable behavior and the emotional security of the child." Further, the disabled child has a right to be a member of a family (Vitello, 1976).

Nearly one-fourth of all developmentally disabled individuals released from institutions are placed in their natural homes (Heal, Sigelman & Switzky, 1978). In many cases, such placements create conflicts between parents and family members, possibly arising from the parental rejection in the original decision to institutionalize, or may reflect fears about again being "burdened with the care of their handicapped child" (Horejsi, 1975). On the other hand, children originally kept at home often have been later institutionalized because of various family crises that appear to make it impossible to maintain the child at home (Thorsheim & Bruininks, 1978.)

In one follow-up survey of children released from public institutions (Willer & Intagliata, 1978) families who did not take their retarded relative home were far more likely to have originally institutionalized their relative due to death or illness in the family, were more concerned regarding the possibility that the female spouse would need to quit or change jobs, and generally had higher incomes than did families who chose to have them return home. Of those who chose to take the retarded person back into the family constellation, many reported the following difficulties:

a) lack of free time to get out of the house,

b) neglect of other family members, and

c) adverse reactions from their own relatives, neighbors or friends.

Such problems related to the care of the developmentally disabled person in the home may be reduced through the provision of appropriate family services.

The provision of needed support services is seen as a source of incentives for retaining the developmentally disabled person in the family home (Skelton, 1972). An important source of support exists in the form of organizations for parents of disabled individuals, in which parents derive support from other parents (Ehlers, Krishef & Prothara, 1973). Counseling services provide another important form of support (Gearheart & Litton, 1975; Katz, 1968; Townsend & Flanagan, 1976).

Recently implemented educational and training support services are also seen as capable of providing incentives for keeping developmentally disabled family members at home. Periodic home visits by an educator or a public health nurse could be of great benefit to the family (Robinson & Robinson, 1976). In addition, programs designed to train parents in ways to normalize relation-

* Much of the material in the next three sections is revised from a chapter on issues in deinstitutionalization prepared by Bruininks, Thurlow, Thurman and Fiorelli (in press).

ships in the family (Ray, 1974) and in the use of special education techniques (Stone, 1975) might not only tend to reduce family problems, but might also have a positive effect on the development of the child.

Foster Care

Foster care involves the placement of a resident, usually a child, with "foster parents" who are paid to provide lodging, meals, and clothing. In addition, foster parents are reimbursed for medical, dental, and other expenses necessary to provide a home for the foster resident. Katz (1968) stresses that while foster care can be used as a transitional residency, the temporary nature and lack of expertise on the part of many foster parents are disadvantages when foster care is provided to retarded individuals. Sternlicht (1978) provides a review of the literature concerning variables of the resident, the foster parents, the community, and the institution which affect successful foster placement.

Justice, Bradley, and O'Connor (1971) described foster placement of children and youth on leave from the Pacific State Hospital. Fifty-nine foster mothers were caring for 195 mentally retarded individuals. The age range was from 4 to 17 years of age, but most individuals were between 12 and 17. About one-half were considered to be profoundly or severely retarded. The foster mothers reported that problems involved:

(a) public misconceptions about mental retardation and lack of acceptance in the community,

(b) school problems resulting from inadequacies and personnel conflicts,

(c) lack of other supportive programs such as recreation, day care, and workshops,

(d) behavioral problems of the child,

(e) lack of medical and/or dental care in the community,

(f) problems with the supervising agency, and

(g) problems with the natural parents.

The foster mothers said that more recreation or activity programs, day care, and workshops for pre-vocational and vocational training were also needed; some of the foster mothers exchanged services so that they could have an afternoon or evening off, but still required service provision for longer periods of time.

Willer and Intagliata (1978) found that foster care providers encountered several problems in caring for retarded people formerly in institutions, namely:

(a) a high frequency of behavior problems,

(b) intensive supervision demands,

(c) lack of free time,

(d) neglect of other family members, and

(e) problems with reactions of neighbors, relatives, and friends.

As pointed out in the Justice, et al. study (1971), other supportive programs providing habilitation opportunities are necessary to support foster placements. These habilitation services are equally important for supporting the other residential alternatives discussed previously.

Respite Care

Respite care is an important support service for families and other caretakers of developmentally disabled individuals in the community (Jaslow & Spagna, 1977). Respite care involves the short-term placement of a developmentally disabled person in a setting outside the family home so the family can obtain some relief or respite from providing the care needed by the individual (Katz, 1968). In most cases, respite care is provided by a temporary foster home, a hospital, or an institution for from one to thirty days (Rodman & Collins, 1974). The need for respite care may arise as a result of several factors. Temporary care services may be needed in cases of emergencies (e.g., illness, death), to permit parents to have a vacation or move (Aanes & Whitlock, 1975; Ray, 1974; Skelton, 1972), to obtain relief from the 24-hour care that may be required, or to avoid possible physical, emotional, and psychological exhaustion (Gearheart & Litton, 1975; Katz, 1968). The need for relief is commonly noted by natural parents and foster parents caring for developmentally disabled people (Willer & Intagliata, 1978).

The provision of respite care as a community service for families of developmentally disabled persons is viewed as a major factor in preventing institutionalization or reinstitutionalization (Gearheart & Litton, 1975; Pres. Comm. on M.R., 1976; Skelton, 1972). Aanes and Whitlock (1975) suggested that the help provided by respite care can effectively be utilized by group homes and other residential care facilities, as well as by parents seeking relief.

A decade ago, Katz (1968) noted that "despite (respite care's) obvious value to the retarded person, his family and the community, there are only a few programs which provide this care." More recently, Bruininks, Williams, and Morreau (1979) reported that 75% of those responding to a survey on issues of deinstitutionalization in six states indicated that respite care services were not available or available only on a limited basis in their states. Over half of the respondents indicated that program assistance was needed in their states to develop and expand respite care services. In spite of this widely recognized need, there is still too little financial incentive for facilities to provide respite care to families with developmentally disabled children.

Conference Proceedings

The proceedings of the Conference on Family Care of Developmentally Disabled members address a number of significant social, economic and programmatic issues involved in providing family-oriented care to developmentally disabled people. Six major papers from the conference address psycho-social factors and economic

factors in family care, and a seventh analyzes the known projects in the nation which are piloting various family support services.

A brief summary highlights some of the key issues raised by the conference presenters and summarizes the results of small group structured discussions involving all the conference participants.

The appendices to this report also contain important information on trends and practices in family care of developmentally disabled members. Several directors of innovative service programs for families attended and participated as resources in the conference. Brief profiles of these projects can be found in Appendix A. Appendix B contains an informative annotated bibliography on aspects of family care. The list of conference participants is contained in Appendix C.

The presenters and persons attending this conference have addressed in a most incisive manner some of the important issues involved in providing and improving family care for developmentally disabled people. Through this report, we hope that the level of discussion can be improved among policy makers in addressing important and often unmet needs of developmentally disabled people, of members of their families, and of others concerned with improving services under the general rubric of family care.

SOCIAL AND PSYCHOLOGICAL FACTORS IN FAMILY CARE

CHARLES R. HOREJSI

UNIVERSITY OF MONTANA

Not many years ago, there were only two options available to developmentally disabled individuals and their families. The handicapped person could either remain with his family or enter an institution. With the first option, the family and the handicapped individual were more or less on their own; there were few community resources from which to draw support and assistance. They struggled with their problems and coped as best they could. If individuals were to be admitted to large multi-purpose institutions, they would have access to some special services, but institutional environments left much to be desired. The longer they were to remain, the less likely they would ever return to their family and the less able they would be to function outside of the institution.

Gradually, a third option developed; namely, the network of programs we term community-based services. This new system of community-based services now stood between the family and the institution. Fewer persons went into institutions and some left the institutions and entered community programs. Of interest, however, is the fact that the flow of handicapped persons out of the family continued. Instead of going from family to institution, handicapped persons moved from home into community residential programs. Few of those leaving the institution returned to their families.

It is my understanding that this conference hopes to take a closer look at family care as an alternative to both community residential programs and institutions. An examination of family care must grapple with many complex questions. Is family care a viable option? If it is, for what kinds of families, for persons with what types of handicaps, and under what circumstances? Is it, for example, workable in two-parent families but not in single-parent families or in families where both parents work outside the home? If it is an option for some families, for what length of time is it workable? Are there stages in the family life cycle when it is an option and stages when it is unworkable? Is it possibly an option in situations where the handicapped person has never left home, but unworkable once the disabled person has left home and spent time in either a community group home or an institution? Can the ordinary family with all of its ordinary problems and concerns adequately deal with the extraordinary problems and concerns presented by a severely handicapped family member? Finally, do existing service programs and public policies encourage or discourage family care? I doubt that

we will have all the answers at the end of this two-day conference. However, if we can identify the key questions and sharpen the issues, our time will have been well spent.

Why Family Care?

We may begin our exploration with the question, "Why family care?" All across the human services, there is a renewed interest in home-based services. Home health care is an excellent example. Sussman (1977) has noted that . . . as services and the population increase, skyrocketing costs for services threaten the society's economy and its ability to maintain existing services or to provide new services . . . Consequently, there is interest in alternative, less costly systems for meeting the needs of dependent populations.

One approach is to examine the extent to which family networks might be able to provide such care, particularly if resources are made available (p. 367).

While it is clear that some of the reasons behind the new interest in family care are economic, and hence political, there are also sound professional reasons for taking a second look at the family as a basic resource for persons with special needs. Skarnulis (1976a) has noted that

The most effective deinstitutionalization program possible is the one that prevents removal of mentally retarded persons from their home in the first place. Most children are not "placed" by their parents but are "taken" from the homes of parents because no alternatives are available (to help the parents cope) (p. 63).

If we can assume that family care is desirable, why do so many handicapped persons leave their homes before the normal age of emancipation? What are the social and psychological forces that "push" or "pull" the handicapped person out of his own home? If we can identify those factors, especially the ones over which we can exert some control, we will be in a better position to provide added incentives for family care.

Definition of Family Care

Before going further I want to explain how I am using the term family care, at least for the purposes of this paper. Obviously, family care exists when a handicapped family member lives with his natural family—either parents, siblings or other relatives. However, I see two types of family care: (1) habilitative family care and (2) ordinary family care. By habilitative family care I am referring to the care, training and supervision of a developmentally disabled person, within the context of his own family, wherein adult family members assume major responsibility for ordinary parenting, socialization, day-to-day personal care and some responsibility for the implementation of individual habilitation plans. Thus, habilitative family care is planned and occurs in conjunction with other support and habilitation services.

In contrast, I apply the term ordinary family care to those situations in which a handicapped individual remains with his family but does not receive appropriate habilitation services. Prior to the de-

velopment of community-based services, most family care was of this type. Unfortunately, there are still many cases of ordinary family care; the developmentally disabled individual lives with his family but does not receive the special services needed. The handicapped individual receives food and shelter and the concern of family members but this care is not supplemented by professional services such as those provided for in P. L. 94-103.

The M-C-O Framework

As a way of sorting out factors affecting family care, I have used the simple framework called the Motivation, Capacity and Opportunity Framework. This construct suggests that the ability of an individual or family to deal successfully with a task or problem is a function of:

1) The *seriousness of that problem* or difficulty of task,
2) Their *motivation* to solve or cope with the problem,
3) Their *capacity* (physical, emotional, intellectual, etc.), and
4) Factors of *opportunity* (i.e., formal and informal resources in their immediate environment and wider social and economic forces).

When the M-C-O Framework is applied to the family of a developmentally disabled child, for example, we would say that the family's ability to provide family care is a function of (1) the seriousness and complexity of the problems presented by the child's condition, (2) each family member's motivation, (3) their capacity, and (4) resources and restrictions in their environment. This framework can be presented as a simple formula in which:

FC = ability to provide family care

M = motivation

C = capacity

O = environmental opportunity

P = problems, needs, demands of developmentally disabled family member.

Thus:

$$FC = \frac{M \times C \times O}{P}$$

In case you have forgotten your algebra, please do not be frightened by this mathematical-like formula. It is simply a framework to which we can attach some ideas about family care. We can play around with this formula and make a few important points. Note that the formula indicates that in order to elevate or enhance (#) the family's ability to provide family care, we must find a way of increasing (#) their motivation or their capacity or the opportunity of their environment. This is shown below.

$$FC\# = \frac{M\# \times C\# \times O\#}{P}$$

The services and supports that increase motivation, capacity and opportunity can be symbolized by (S). Thus, we have

$$FC = \frac{(M \times C \times O)\ S}{P}$$

Most of us associated with programs for developmentally disabled persons are in the business of providing the (S) in the formula. One other important point is illustrated by this little formula. As (P) becomes larger, the ability to provide family care decreases.

$$FC\# \quad \frac{MCO}{P\#}$$

To go one step further, if you want to maintain the family's ability to provide care while the child's problem becomes more serious (P#), you must provide more and more services (S#) in order to sustain their motivation, increase their capacity and/or expand environmental opportunity for family care. One final point can be made. No amount of services can compensate for a complete lack of motivation, capacity and opportunity. Moreover, even if a family has motivation and capacity, no amount of services can compensate for powerful social and economic forces that severely restrict opportunity.

Motivation

Motivation can be viewed as a balance between the "pull" of hope and the "push" of discomfort. We are drawn toward that which we value and we push away from that which creates discomfort. We can tolerate discomfort only when we believe that the discomfort will yield some good in the future. If we apply this simple notion to the issue of family care we may ask, "What social and psychological factors pull families toward family care and what factors push them away?" Needless to say, there is a degree of subjectivity in what people value and what they find painful. Each individual and family is unique. Nevertheless, we can offer a few generalizations.

I think it is accurate to say that once the shock of having a developmentally disabled child subsides, most parents show fairly strong motivation to work with and care for their child, at least during the preschool years and the early years of school. With few exceptions, parents just naturally try to care for their offspring, whether handicapped or normal. Society expects this of parents and our socialization process prepares us to expect it of ourselves. We would feel guilty if we didn't try. That doesn't mean that we automatically do a good job or that we assume the parenting role without reluctance or ambivalence. I am simply trying to say that the majority of parents are inclined to care for their handicapped child until such time that they can no longer cope and/or until professionals advise against it. Thus, a primary incentive toward family care is the reality that parents bear a sense of obligation toward the child's well-being. That sense of caring, love, or moral obligation—what-

ever you choose to call it—may be mixed, of course, with other feelings such as guilt, repulsion, and anger. But my point is that, for most parents, there is a pull toward parenting and family care. If we wish to encourage family care we must recognize that factor, reinforce it and build upon it. In discussing a professional's behavior toward the family, Moyer (1975) makes this same point when she says that

> Feelings of genuine caring and loving must be identified and allied with in order to achieve family commitment to . . . (early intervention) and developmental growth for the child (p. 1).

Most of our public programs and policies do little to recognize and support a family's commitment to care for a handicapped member. Some do the opposite. For example, do we reinforce the concern of middle-income parents when we inform them that their handicapped child is not eligible for Medicaid, Title XX services or SSI so long as he stays home with his family, but that their child would be eligible for these programs if he would leave his family and go into a foster home or a group home?

During the early years of parenting the pull of hope sustains parents because progress, while slow, is fairly tangible (e.g., feeding, crawling, walking, etc.). As the child grows older, progress is less visible and behavior problems become more complex and difficult to handle. Parents begin feeling tired, siblings begin to feel that they are being short changed in the family. For parents of normal children, school provides a welcome respite from parenting. For parents of a handicapped child, school is often a hassle. For example, special education programs work hard at involving the parents in programming; as compared to ordinary school programs, a special education program places more demands on the parents. Thus, parents are introduced to social and psychological costs of obtaining services for their child. As compared to the parents of normal children, they must pay a higher price for six hours of relief each school day.

A recurring theme among the frustrations voiced by parents of developmentally disabled children is that the task of being a parent goes on and on. The tasks to be performed by the parent of a handicapped child are both more intensive and extensive. They demand more of the parents for a longer period of time.

When progress is slow and there is little relief from the burdens of parenthood, many parents lose hope. The hopes and joys of parenthood are outweighed by the discomforts and demands. When a crisis occurs they cannot cope. It is at such a time that they request institutionalization or placement into a community-based residential program. Regrettably, the public and many professionals have operated on the basis of what Skarnulis (1976) has termed the "residential assumption," i.e., a person is assumed to need residential services just because he is developmentally disabled. For example, when faced with a family having a difficult time coping with a handicapped member we usually say, in effect, "We realize your burden is great, and getting heavier. Would you like to consider

one of our group homes?" In subtle ways this residential assumption has undermined motivation toward family care.

In describing his own experience in designing residential programs, Skarnulis (1976b) stated that:

> . . . A parent seldom came to me saying, "I need my boy out of the house seven days a week." They came to me saying things like, "How can I keep him from scratching his sister?" or "We haven't had a chance to join a bowling league or spend a weekend alone together since Jimmy was born." I begin to wonder if we weren't guilty of overkill. They didn't need residential services, they needed ordinary help just like the rest of us. We went along setting up expensive group homes, institutions and foster homes, then expecting people to fit into them (p. 6).

Let me be quick to point out that Skarnulis is not suggesting that community residential options are unimportant. Rather, he is trying to drive home the point that sometimes our programs undercut the family's motivation for family care. All too often we are forced to offer a family the services we *have* or those that can be funded, but not the ones they really want or *need*.

Because of the way our programs are funded and the type of accountability structure that has evolved, we have become preoccupied with the needs and problems of the handicapped person and tend to forget the rest of the family. For example, the language used in P. L. 94-103 to describe the required habilitation plan creates a rather narrow focus on the training and care of the developmentally disabled individual. I am not opposed to habilitation plans; I am simply pointing out that this language encourages an individual focus, not a family focus. If you look closely at our community programs and services you will find that their focus is on the handicapped member, but not on the needs and the problems of other family members or on the family as a whole. For example, we can provide sophisticated diagnostic services but little in the way of homemaker or chore services. It is quite easy to find funds for a wheelchair but nearly impossible to find money for a washing machine. We can send a handicapped member to camp but cannot help a family have a summer vacation.

During moments of discouragement, when I look at the way we fund family support services and at who is eligible to use them, I wonder if we have created a sort of "psychological means test." You will recall that the way the economic means test works for SSI or Medicaid is that you must spend down or get rid of all your economic resources before you are eligible for financial assistance. Once you have destroyed yourself financially, you become eligible for assistance. It is as if, by placing yourself in a genuine financial emergency, you have proven the legitimacy of your claim for outside resources. I see something similar operating in our family support programs. We seem to be able to offer services once the family has nearly destroyed itself or is in a genuine crisis, but don't do much to prevent the destruction in the first place. In a sense, we ask families to "spend down" their emotional and psychological resources be-

fore we can offer a revelant service. We ask families to fit our services rather than make our services fit the family.

Capacity

Let's move on to the area I have called capacity. Aside from motivation, what are the prerequisites for successful family care? A few simple questions will serve to identify some of these and highlight possible incentives and disincentives for family care.

How about time and energy? Family care takes a lot of it. Assuming that support and habilitation services are available, do parents have the time and energy needed to utilize those resources? I think experience demonstrates that if the use of family support services demands more time and energy than it saves, families soon lose interest. It is a simple matter of response cost. The use of support services must make life less hectic, not more hectic.

Do parents and other adults in the household have the capacity to meet the needs of the handicapped member without short-changing or neglecting the other children in the family?

Do parents, older siblings and others in the household have the knowledge and skills needed to actively participate in individual habilitation plan meetings and carry out their part of the plan?

Do significant family members have whatever it takes to work under professional supervision and learn skills needed to care for a developmentally disabled individual with a severe physical involvement?

Does the family have the financial capacity to handle the extracrdinary costs of family care?

Does the family have the ability to cope with neighborhood cranks, public misunderstanding and prejudice against persons who are developmentally disabled?

Do parents and siblings have the energy to fight for the services they need and, when necessary, question the judgments or actions of professionals and agencies?

Are the relationships among all the people in the family, especially the parents' marriage, strong enough to withstand the demands of family care?

Are siblings, especially during the teen years, willing and able to take on some of the family care responsibilities?

Can family members find satisfaction in record keeping, baselining and other activities that are part of home-based service delivery?

Do family members have the objectivity and even the emotional detachment that may be needed to provide a systematic home training and to deal with the behavioral problems of a family member?

Do parents and siblings have the patience and understanding needed to allow their child to experience the joys and anxieties of a sexual awakening during adolescence and early adulthood?

Another way of looking at capacity is to place the question within the context of basic human needs. If we start with the as-

sumption that all people have certain needs and that much of our behavior is an attempt to meet those needs, it follows that unless family members are able to meet their individual needs while being involved in family care, family care is unworkable.

Aside from food, water and shelter, we have a need for physical safety and security; things so basic as decent housing and safety are essential ingredients for family care. We all have a need to be respected and valued. Thus, a family engaged in family care must have the continuing respect and approval of significant others such as friends, relatives, neighbors, employers, etc.; family care must give people a feeling of being worthwhile and useful, but not used. We have a need for affection and for achieving some degree of intimacy with others; family care must not interfere with the development of such relationships. We have a need to know that we are not alone in how we experience life and see the world; family members must be able to discover that others also share in the joys and frustrations of family care, and must not be made to feel that they are alone. Each human being struggles in his own way to figure out what life is all about. There seems to be a need for some kind of a philosophy of life. This may be especially important to persons devoting their life to the care of a handicapped family member. Finally, humans have a need to play, to try out new experiences, to experiment with novelty and do some things just for the hell of it; family care must never become so oppressive or routine that the family loses all spontaneity, humor and sense of adventure. The question for those of us interested in expanding family care becomes one of how we can make it possible for family members to meet these basic human needs, each in his own unique way, while they assume extraordinary responsibilities.

Additional perspective on the capacity factor becomes apparent when we think about the economically poor family and the so-called multi-problem family. Family care will be particularly difficult for the low income family; the family in poor and overcrowded housing, the family living in an unsafe neighborhood, and the family in which more than one member has serious physical, social or psychological problems. The demands of day-to-day survival for these families is such that there is little time or energy available for the direct care of a seriously handicapped person and the necessary involvement with the many professionals and programs that are a part of habilitative family care.

Systems theory suggests that when a family relationship is unsatisfactory, when the give and take of family life is not meeting the needs of the people in that family, two things commonly happen: (1) the family continues to disintegrate, or (2) the family tries to repair itself through "repeopling." The term "repeopling" is used by some family therapists to describe the family's effort to cope with problems by changing the number of people in the system, by either adding people or excluding people. Asking grandmother to move in with or move out of a family is an example of repeopling. It is a sign that says, "In order to preserve our family system, we must remove

one component of the system." What I am trying to suggest is that family care is workable only so long as members of the family can meet their individual needs while engaged in family care. The services used to support family care must somehow tune into those basic human needs and help each family to meet those needs. Stated differently, support services must reduce the negative effect family care may have on an individual's ability to meet his own needs.

Systems theory also tells us that a family attempts to maintain a steady state, a predictable pattern of behavior and activity, that is resistant to change. If that steady state is disrupted, a new one would be established in a matter of weeks or months. This notion of steady state helps to explain why, after a handicapped family member has been placed out of the home, the family usually resists his re-entry into the family system. Once the handicapped member leaves the family, and if there is little or no contact between the individual and the other family members, the family builds a new set of relationships. Each family member establishes a new pattern of need-meeting behavior. Anything that threatens the new family pattern will be resisted. The implication is clear. Once the handicapped family member leaves the family, the possibility of re-establishing family care is greatly reduced. If we are serious about family care we must be able to provide the supports that prevent initial out-of-home placement. Parenthetically, let me suggest that research in foster care indicates that, once a family member is absent for a year, reintegration becomes increasingly difficult.

OPPORTUNITY

Now a few comments about opportunity. Within the M-C-O Framework, motivation and capacity relate primarily to factors within the family system and between family members. The factor of opportunity applies to what goes on between the individual family and the community. It also applies to forces in wider society, ones well beyond the control of the individual family.

The normalization principle rests on the assumption that, if developmentally disabled individuals live with normal people in normal communities and under normal conditions, they would have more stimulation, more growth experiences, and come as close as possible to achieving their maximum potential. Basically, I agree with that position but, for the purpose of making a point about family behavior, let me say that it "ain't necessarily so."

Butler, Bjaanes and Hofacre (1975) observed that:

To provide a normalizing environment, community care facilities must provide an environment which is enriched both with internal programs and external contact and exchange. If either is lacking, a deprived environment will tend to develop which will effectively hinder the normalization process (p. 10).

The same thing can be said about family care. Unless the family is enriched by internal programs and by contact and exchange with persons, groups and organizations external to the family, it may

offer the handicapped member a deprived environment which provides little stimulation and, in some cases, a highly restricted life experience. Some families, like the old custodial institutions, may encapsulate the developmentally disabled person in an overprotective artificial world. Given the demands of caring for a handicapped person, many families withdraw from contact with others. In order to conserve scarce time and energy, both physical and emotional, the family turns inward and avoids contact with external systems. In doing so, it reduces opportunities for the handicapped person to interact with persons outside the family and the "normal" world beyond the family.

If a family is going to provide habilitative family care, it needs to be involved with professionals, agencies and programs. The dynamics of these relationships must be considered in any serious look at family care. Frequently one hears professionals express frustration and sometimes anger with parents who do not follow the treatment or training plans designed to help the handicapped child. In extreme cases, professionals feel that parents are just getting in the way of sound professional procedures and decisions. On the other hand, parents often express frustrations and even anger with professionals who make suggestions or design training programs to be carried out by the parent. They say that the plans fail to consider the realities of family life and the heavy demands of maintaining a household. Some parents complain that they are made to feel guilty because they do not do what the professional wants.

In order to "stir up the pot" allow me to offer a few personal observations. Almost by definition, family care means that the parents are the essential and primary providers of care. It is they, not the professionals, who have assumed responsibility for care and training of the handicapped member. Professionals should expect them to behave like parents and family members, not like professionals. Since parents have assumed the responsibility and burden of care, their efforts must be supported and sustained. Professionals must demonstrate trust in and respect for the parents' decisions, their life style, their values and beliefs, and their efforts to care for the handicapped family member. This may mean that professionals have to make some rather significant compromises as to what they think is best for the handicapped individual and what is, for example, good training practice or technique.

We cannot approach family care as if the family was a group home, a special education classroom, or a clinic environment. As Perske (1973) says, there are no ideal families, " . . . there are only messy ones with . . . strengths and weaknesses" (p. 47). Family life is not neat and clean. It is often chaotic with internal conflict.

Family members that provide family care do what they do because they are parents, brothers or sisters and because, in their own unique ways, they care about the handicapped family member. If a professional treats family members as if they were handmaidens, someone to carry out the professional's order or plan, the professional destroys the very thing he wants to create, i.e., a normal

family environment for the handicapped member.

I would like to draw my paper to a close with some remarks about broad societal trends, factors of opportunity far beyond the boundary of the individual family. The American family is undergoing rapid and significant change. There are many types of families. The standard nuclear family (husband, wife and their offspring) is still a dominant form, but only about 37% of the United States families are of that type (Sussman, 1977, p. 359). We must recognize the growing number of single-parent families (one parent plus children), remarried nuclear family (husband, wife and offspring from previous marriages), kin network families (three generation or extended families), and single and relative families (composed of single, widowed or divorced relatives living together with children). In addition, there are a growing number of experimental types such as the commune family and unmarried couples with children.

In the process of working on this paper I reviewed some of the mental retardation literature that focused on family dynamics and family support services. With few exceptions, writers discuss parental and sibling reactions, techniques for parent counseling, approaches to home training, etc., as if there were always two parents in the family, as if a handicapped child never acquired stepparents and stepsiblings, and as if the mentally retarded child never experienced the problems of having parents separate or divorce. Needless to say, a divorce or separation has significant short-term and long-term effects on the family's capacity to care for a handicapped member.

Keniston (1977) states that:

> . . . today about one out of every three marriages ends in divorce and more and more of them involve children . . . It is now estimated that four out of every ten children born in the 1970's will spend part of their childhood in a one-parent family, usually with their mother as head of the family (p. 4).

If one includes marriages broken by informal separation and desertion, the rate of family breakup would exceed the one out of three cited above. At least 40% and perhaps 50% of the developmentally disabled children will spend part of their childhood in a one-parent family. Many others will live in families that are different in some way from the traditional nuclear family. Given the demands of caring for a handicapped child, our high rate of family breakup and the growing number of one-parent families may prove to be powerful countervailing forces to any significant expansion of family care.

Inflation and the high cost of living, especially for housing, have pushed a growing number of mothers into the work force. Two incomes have become essential for many families, especially those who want to fulfill the American dream of owning their own home. Families with a developmentally disabled child are not immune from this economic pressure. If anything, they feel it more intensely. In addition to the economic crunch that is pushing mothers into the work force, the women's movement has drawn many mothers out of

the home. A growing number of mothers with young children want to move beyond the parent role and find other sources of personal satisfaction. This desire to be something more than just a mother and housewife is also felt by the mothers of developmentally disabled children.

Keniston (1977) states:

In 1948 . . . only 26 percent of married women with school age children worked at anything but the job of keeping house and raising children. Now that figure has more than doubled: in March 1976 54 percent worked outside the home, a majority of them full time. The increase in labor-force participation is even more dramatic for married women who have pre-school children . . .

. . . we have passed a genuine watershed. This is the first time in our history that the typical school-age child has a mother who works outside the home (p. 4).

These broad social and economic trends are well beyond the influence of national, state or local developmental disabilities programs and planning bodies. They are, however, realities that must be considered. Those who may want to encourage family care must find ways to fund and deliver relevant assistance and support services, regardless of family type or structure. Much of our public policy and many of our public programs are oriented to the nuclear family; non-traditional families have a hard time meeting the eligibility requirements of some programs. We are going to have to be much more innovative and more flexible than in the past and we are going to have to change many state and federal laws and programs that only fit the traditional nuclear family.

SOCIOLOGICAL AMBIVALENCE AND FAMILY CARE
The Individual Proposes and Society Disposes

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The key question raised by Charles Horejsi in his paper is whether family care is a viable option as a strategy for handling developmentally delayed children. His paper then lays out a series of social and psychological factors "that seem especially relevant to the planning and development of programs designed to support or encourage family care." He organizes these factors in terms of a Motivation-Capacity-Opportunity (M-C-O) framework. Applied to parents of a developmentally disabled child, the framework indicates "that the parents' ability to provide family care is a function of the parents' motivation, their capacity, resources in their immediate environment, and the seriousness and the complexity of the problems presented by the child's handicapping condition." According to the framework, "if you want to maintain the family's ability to provide care while the child's problem becomes more serious, you must provide more and more services in order to increase their motivation, capacity and opportunity."

"Is family care a viable option?" My comments will suggest a response which is different from Horejsi's to this question. I shall first discuss the M-C-O framework as a version of the medical model of treatment applied to social problems. My discussion will imply that, since the model does not focus upon the sources of the social problem, any treatment based on that model is symptomatic and cosmetic. Secondly, my commentary will deal with the problem of social contradictions faced by parents of developmentally disabled children. Here, I shall try to show how sociological ambivalences of various kinds impinge upon the destinies of these families and their children. Finally, I shall propose that a more sobering, realistic view may actually enhance the ability of families to cope with their handicapped children. This view takes into account the sociological ambivalences inherent in family relationships.

THE M-C-O FRAMEWORK AND THE MEDICAL MODEL

The medical model of therapy has been enormously successful in the treatment of physical illnesses. According to this model, a practitioner diagnoses an illness or malfunction and prescribes certain medicines or procedures for remediation. Because of these ministrations, the patient is restored to a normal state. Since the model has been so successful in medicine, many social practitioners have

applied it to social problems. But its use in the remediation of social dislocations seems to neglect what is truly social and focuses instead upon the "problem persons" themselves. It is mainly this difficulty that I find with the M-C-O framework as a derivative of the medical model.

The phrase "blaming the victim" has become commonplace in social science. The implication, of course, is that the problem at hand is generated by some sort of defect or deficiency in the sufferer himself (or herself). If the deficiency were somehow removed, then the problem would be resolved. This phrase has been applied to a large variety of social problems—racism, sexism, alcoholism, drug abuse, delinquency, and so on. Some people attribute its source to the medical model of treatment; others attribute its derivation to the helping professions in general. Regardless of the source, the personal (or group) deficiency model assumes that a consensus exists as to what is deficient and how to treat it.

The M-C-O framework presented by Horejsi lends itself to the interpretation that it blames the victim—the family of the developmentally disabled child—for its failure to cope with problems of dealing with that child. Not only that, but the family should be encouraged to "normalize" the child and not to use him or her in order to solve other difficulties the parents may have. Accordingly, Horejsi proposes that professional services bolster family care whenever family motivations or capabilities are insufficient. However, Horejsi begs the question of criteria of insufficiency.

In indicating the need for preventive measures, Horejsi furthermore suggests that we should not wait for a family to expend itself emotionally—as passing a sort of means test—before providing assistance. Still, a basis must be established for allocating limited resources. Moreover, if respite assistance is to be available to families with retarded children, why not others as well—the cerebral palsied, the severely physically handicapped, the invalid parent, the aged? Add to these the possibility that "fraud" is inherent in the medical model. Since there is no consensus on measures for suffering or for "need" for services, we can expect malingerers to make use of the fact that the helping professions are motivated to include questionable cases in the group requiring help. One thus encourages a continual expansion of the helping industry, perhaps geometrically, as "need" expands linearly. Personally, I don't mind this expansion, and in some ways welcome it. But the same kind of overburdening of facilities that occurred for residential institutions may eventually create much dissatisfaction with the helping professions, being so overburdened that their resources are squandered.

The medical model presupposes that motivation and capability reside within people, like gall bladders and livers, and that deficiencies can be compensated for by therapies or respite-help. (See also Lewis, 1978.) The medical perspective ignores the fact that the major factors in adapting to a developmentally delayed child appear to lie outside personal control, in society itself. Larger social forces seem to mold the person's view of how the world operates and of the

interpretation of disappointing or noxious events. Motivation and capability are influenced by one's religious beliefs, the parents' educational background, the presence of normal siblings, the existence of supportive kin and friends, and especially interaction in one's own family of orientation (Farber, 1959; 1960; Farber, Jenne, and Toigo, 1960).

In a study dealing with young women's perceptions of what they might do if their children were born grossly deformed, I found that earlier authority patterns in their families of orientation were more effective in predicting their views than were any concurrent factors, including their life style and present relationships with their parents. The earlier interaction patterns seem to have laid a foundation for their conceptions of legitimate family responsibilities. This earlier family interaction is itself a function of such elements as socioeconomic factors, ethnic and religious background, and other societal variables.

The research sustained the following hypothesized relationships between specific parental authority patterns and daughters' family role orientations:

(a) Egalitarian parental authority in adolescence is associated with the adult daughter's unconditional child orientation, which implies a firm commitment to home care over a career and a rejection of infant euthanasia.

(b) The presence of divided spheres of authority between the teenager's parents is associated with the daughter's later commitment to a strong home role orientation. This orientation gives priority to home care over career, but it does not reject euthanasia of newborns.

(c) Earlier maternal dominance is associated with the grown daughter's "right-to-life" orientation, which gives preference to career over home responsibilities while rejecting euthanasia of newborns.

(d) Paternal dominance is associated with the daughter's unconditional career orientation in adulthood. This orientation not only values career over home responsibilities but also favors euthanasia of grossly deformed newborns.

These findings suggest that the variation in amount of risk that a young woman is willing to take in adapting to a severely defective child is a function of past interaction patterns in her parental home. At one extreme, a young woman from an egalitarian home is more often willing to go all the way in doing whatever is necessary to care for such a child. At the other extreme, the woman whose home had been dominated by her father tends to down-grade home and family responsibility (Farber, 1978).

Even permeability of the family to outside influence is not simply an individual matter related to a motivation to care for the child, family resources, or environmental opportunities. This permeability is influenced in part by religious and ethnic characteristics associated with extended family and communal ties. For instance, Jewish

couples, more than others, involve relatives and professionals in their decisions regarding institutionalization of retarded children, Catholics somewhat less, and Protestants least (Farber, Jenne, & Toigo, 1960). This tendency is also revealed in the use of mental health services and concern over children's health (Lurie, 1974; Srole, Langer, Michael, Opler & Rennie, 1962). The professional role in the decision-making process must obviously vary with the permeability of the family.

To summarize, (1) the M-C-O framework seems to assume that a consensus exists as to what is deficient and how to remedy this deficiency, (2) it would expand the helping industry beyond its capabilities, and (3) it ignores the fact that the major influences in coping with problem children derive from factors which are beyond control of the families.

SOCIAL CONTRADICTIONS AND PERSONAL PROBLEMS

In dealing with conditions over which families have little control in coping with a severely developmentally disabled child, I propose to focus upon the limitations of assistance intended to alleviate family problems. In doing so, I shall suggest that there are difficulties inherent in long-term family care for the developmentally disabled and that the social context of contemporary society itself operates to counteract attempts at remediation of problems which emerge in the course of family care.

The current world-view with which we operate informs us that, increasingly, technology and modernization of culture have brought a large measure of control over our environment. For a measure of social progress we look to history, and history does reveal many effects of modernization—such as increase in length of life, heightening of quality of life, and greater realization of human potentiality. The decline in infant mortality rates, the virtual elimination of epidemics, and decreases in widespread famine have all lent support to the perspective that we are progressively gaining control over those elements which are destructive to human life and society.

The view that external constraints to the realization of human potential can be dissipated has been extended to personal relationships as well. Contemporary writings on the family emphasize a trend toward the liberation of one's personal life from legal restrictions, moral tradition, and other communal limitations (e.g., Skolnick, 1978). Current ideas about family life are articulated in terms of independence, individual rights, and self-realization. Indeed, this optimistic view has been extended far beyond the reaches of the family into all aspects of contemporary American society. Media of mass communication and mass entertainment promise immediate no-cost gratification, civil rights for all, instant success, a cure for every illness, and an illness for every cure. The notion that all deficiencies can somehow be remedied implies that someone, usually a professional specialist, is available to remove whatever im-

pedes the American Dream. It is my theme that we have oversold this dream.

The plight of families with severely handicapped (especially developmentally delayed) children seems to illustrate the consequences of overselling the American dream. The freedom from constraints about which many writers comment must seem illusory to these families. The parents are caught in a cross-current of contradictions about social expectations. They live in a society which advertises freedom and self-realization on the one hand, but which ascribes tremendous responsibilities for them in caring for their disabled children; they are taught that familial relationships should be fulfilling, and then are presented with a reality which fosters withdrawal and heartache; they are imbued with a concept of childhood that implies development and eventual intellectual maturity, and then are assigned the task of caring for a child who will never attain these aims. The family of the developmentally delayed child is between two worlds, the normal and the deviant, and contradictory social expectations often pull it in opposite directions.

The concept of "sociological ambivalence" can be applied to describe this contradiction. The substance of what Robert K. Merton has called "sociological ambivalence" has endured as a focus of concern over a series of generations. For Merton (1976), "sociological ambivalence in its core sense refers to opposing normative tendencies in the social definition of a role" (p. 12).

In earlier writings, particularly those at the beginning of the twentieth century, sociological ambivalence was seen primarily as an aspect of transition from a feudal society to a modern industrial state. The concept of "the marginal man" was applied by Everett V. Stonequist (1937) not only to "those individuals who fall between two major racial or cultural groups, but also . . . in the relations of minor groups such as social classes, religious sects, and communities." Specifically, the marginal man is one "who through migration, education, marriage, or some other influence leaves one social group or culture without making a satisfactory adjustment to another (and) finds himself on the margin of each but a member of neither" (pp. 2-3). In his depiction of the stranger as a social type, Georg Simmel (1950) observed that the stranger's objectivity in social relations "is a particular structure composed of distance and nearness, indifference and involvement" (p. 404). These opposing tendencies served to give the stranger a unique status and role in a community.

At mid-century, the focus in the study of sociological ambivalence shifted from the transition to an urban society to the complexity of modern social structure. Noting that occupation, income, education, and ethnicity each produce a ranking of social status, Gerhard Lenski (1954; 1956) sought to determine the cross-pressures upon individual conduct deriving from inconsistencies in ranking on these attributes. He proposed that "persons with a low degree of status crystallization are more likely to be subjected to

disturbing experiences in the interaction process and have greater difficulty in establishing rewarding patterns of social interaction than others" (Lenski, 1956, p. 459). Since then, the consequences of status inconsistencies for mental health, political views, and other attributes have been studied. The contradictions generated by conflicting expectations thus tend to permeate a wide range of relationships. I suspect that these conflicting expectations underlie the persistent profound problems facing families with developmentally delayed children.

Despite the vast increase in services to the developmentally disabled over the past thirty years, the major family problems remain the same. In his paper, Dr. Horejsi remarks, "A recurring theme among the frustrations voiced by parents of developmentally disabled children is that the task of being a parent goes on and on and on." It was this same theme that I heard from parents in the 1950s when I undertook my research on families with severely retarded children and, apparently, it is still prevalent today. In fact, the interpretations of the data that I collected were, in large measure, based upon the proposition that the presence of a severely mentally retarded child in the family inhibits the development of a normal family life cycle. (See also Birenbaum, 1970.) My conception of arrest in the family life cycle took the following form:

1. In interaction with their children, parents tend to assign a status to each child commensurate with the capabilities they impute to him.

a. The roles embodied in the status are classified on the basis of age grading. By definition, normally, mental age is approximately equal to chronological age.

b. Age grading in a culture is regarded more as a psychological and social activity than as a chronological variable, e.g., the chronologically middle-aged severely retarded individual is generally regarded as a "boy" or "girl" by those with whom he interacts.

2. As the child proceeds in his (life) career, the parents normally tend to revise their self-concepts and roles. With respect to their normal children, ideally, parents continually redefine their roles, obligations, and values to adjust to the changing roles of the child. With respect to their retarded children, the parental role is fairly constant. Regardless of his birth order in the family, the severely handicapped child eventually becomes the youngest child socially.

. . .In his progressive movement to the youngest-child status, the severely retarded child would not merely slow down movement in the family cycle but also prevent the development of the later stages in the cycle (Farber, 1968, p. 158, from Farber, 1959).

Drawing upon this conception, I suggested several latent consequences for other family members:

1. A role conflict for siblings, i.e., a partial shifting of roles for the siblings to being caretakers, with a heightened sense of responsibility and possibly resentment for leading a life which suffers by

comparison with "childhood" expectations of peers in "normal" families (Farber, 1959; Farber and Jenne, 1963).

2. Being *in* but not part of the "normal" community, i.e., an uneasy sense of difference from other families, especially as the child grows older; often social and occupational withdrawal. Families often maintain their integrity by isolating themselves and giving up the usual criteria for success, such as high sociability or occupational mobility (Culver, 1967; Farber, 1968).
3. The cross-current of home versus career for middle-class women, i.e., keeping the mother in the preschool stage maternal role, the period of motherhood in which outside occupations are least sought. Hence, mothers would be less likely to seek outside employment.
4. Concern of future contradictions, i.e., depending upon the parents' orientation toward the future, some parents would anticipate the arrest in the family cycle rather than merely experience it. While they all would try to develop strategies for counteracting its effects, for many the enormity of the domestic tragedy which the future held would lead to much mental anguish. Since middle-class parents more often than working-class parents focus upon the future, one would expect this anguish of anticipated family-cycle arrest to occur mainly in middle-class families (Farber, 1960).

In his discussion of structural sociological ambivalence, Merton directs our attention to the conflicting demands inherent in a single role. These demands, he writes, generate oscillation between conflicting aspects of a social relationship. For example, every nonascriptive (i.e., revocable) social relationship must at the same time establish norms for fulfilling whatever tasks are involved, and simultaneously it must also contain the seeds for its own destruction—how is the relationship to be brought to a conclusion legitimately? Children vacillate in-between parents and peers seeking approval over their actions; lovers manufacture quarrels; subordinates test the limits of tolerance. In revocable relationships, there must be a point at which the destructive elements are supposed to predominate. Merton (1976) sugests that "this alternation of subroles *evolves* as a social device for helping people in designated statuses to cope with the contingencies they face in trying to fulfill their functions"(p. 18). An undercurrent of conflict and quarreling is more threatening in a life-long relationship than in a voluntary, fleeting one not only because of the discomfort it may produce but also because this undercurrent signals to the participants the fact that, in a significant way, the relationship resembles a revocable one.

The conception of arrest in the family life-cycle may also reveal something about the long range consequences of the presence of a developmentally disabled child in the home. For the severely developmentally disabled person, norms in the family of orientation do not provide an opportunity for revocation. Hence, the ordinary sig-

nals for revocability may become a threat to the strength of the bonds between the disabled person and his (or her) parents and siblings; instead of welcoming even a limited development of social and economic independence, emergence of quarrels and conflict, and growing apart emotionally, parents may want to suppress them in order to make life a little easier over the years. It is little wonder that parents of developmentally disabled children are frequently seen by educators, psychologists, and social workers as overly protective.

Perhaps the most significant consequence of the absence of the norm of revocability of domestic roles is the frustration of normalization of the disabled child. The lack of an undercurrent of revocability in turn leads to problematic terminations of familial ties. In the book, *Cloak of Competence*, Robert Edgerton (1967) sets forth the proposition that adult mentally retarded persons generally are able to live in community settings because of the continual sponsorship of a parental surrogate—a relative, a close friend, a neighbor, an employer, a social worker, and so on. This person acts as a manager of the retarded person's personal, employment, and financial affairs. But Cunningham (1976) suggests that:

Sponsorship, however, seems to be a two-edged sword: it provides a series of benefits to the person sponsored, but it may also limit the potential adult role performance of the person sponsored and . . . may be withdrawn by the sponsor at the sponsor's option. As with most roles which include dependence on another, the retarded person live(s) a precarious existence (p. 65).

Hence, without an undercurrent of norms signaling the legitimacy of revocability of domestic roles in the case of developmentally disabled children, several problems emerge: (1) role contradictions stemming from arrest in the family life cycle, (2) the overprotectiveness by the parents, (3) uncertainties in the later stages of the family life-cycle, and (4) the handicapped person's being at the mercy of the parental surrogate's good will. The social contradictions which impinge upon families with severely mentally handicapped children seem to amplify the ambivalences and cross-currents which other families ordinarily endure.

BRINGING SOCIAL REALITY BACK IN: THE NORMALITY OF DISAPPOINTMENT

In the past thirty years, how much have we done to assist parents of developmentally disabled children? No matter how we disguise a bitter pill, it is still a bitter pill. We can use linguistic subterfuges; we can offer sops of "respite care" in order to co-opt parents; we can give special training to parents and siblings to help cope with everyday contingencies; we can organize parents to commiserate with each other over their disabled children and to seek common solutions for an unending list of problems. We can do all these, but we cannot eliminate the idea of tragedy and disappointment. Dr. Horejsi tells us that, when all is said and done, the responsibility for

the developmentally disabled child rests with the parents, that "the very thing *we* are trying to achieve . . . (is) allowing the handicapped person to live with his or her family." With the closing off of institutional admissions, parents are more often forced into family care; the child is there, and all we can do for the parents, as in the case of the terminal cancer patient, is to make life a little more palatable and to ease the pain. But at the same time, we subtly inform parents that if they cannot cope with the problems of handling their developmentally delayed children, they themselves are somehow defective or deficient.

Because of modern technological advances, we all are led to exaggerated expectations in every area of existence. During the last part of the nineteenth century, the rapid economic development in Western society gave rise to the myths of open upward economic and social mobility. Today, a similar optimism seems to pervade the society in areas of personal relationships. Many observers attribute the current high divorce rate and the continual seeking of alternative domestic life styles to the exaggeration of expectations of what one should get out of marriage and family life. Indeed, one of the consequences of isolation of family units is the ignorance of the frustrations and disappointments that go on in other families. Privacy in the contemporary family not only permits "alternative life styles," but it also enables people to display an "optimistic" and "happy" front to the world. Most important, this "optimism" of exaggerated expectations becomes the norm, the model of domestic existence. This is the social context in which the parents of a severely disabled child find themselves. People are led to believe that suffering is abnormal, that any disappointment constitutes some sort of deviance.

Still, whereas technological control has advanced with incredible speed, most of us can expect to endure much disappointment and suffering during our lifetimes. Despite our emphasis upon the achievement of "success"—family success, educational success, economic success, and, mainly, success in interpersonal relations—there is no earthly paradise, there is no "soma" pill, and no solution for many problems. All relationships—even between the helping professionals and their clients—have elements of disappointment. One might say that disappointment is a necessary undercurrent, a negative aspect of a sociological ambivalence, in any sustained interaction. Some of us are luckier than others and have an obligation to diffuse our luck. But we also have an obligation not to try to oversell our product, our assistance to the unlucky.

Without acceptance of disappointment as "normal," as Emile Durkheim recognized almost a century ago, human wants are insatiable and, as a consequence, when dreams are not realized, despair is deepened. The normality of disappointment seems to have disappeared in the optimism of the twentieth century; with its disappearance, the burdens of failure are magnified. It is not merely motivation and resources, but also what the family *expects* to happen that

determines the kind of environment it can provide in caring for the developmentally disabled child. Parents are led to maintain their illusion that a worldly Nirvana or secular grace is possible. Failure to recognize the inherent contradictions in all social relations serves to heighten problems in families with developmentally disabled children. In refusing to consider disappointment and tragedy as normal modes of existence (as concomitants of achievement), we magnify frustration and suffering for families with disabled children: We then blame them for failing to achieve the Modern Dream.

AN ECONOMIC MODEL OF SOCIAL AND PSYCHOLOGICAL FACTORS IN FAMILIES WITH DEVELOPMENTALLY DISABLED CHILDREN

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In recent years, the study of economics has been applied with some considerable success to psychological and sociological problems. My object here is to develop an economic model of the family with a disabled child. Such a model is empirically testable, quickly leads to certain policy conclusions, and reinterprets, as rational economic behavior, various characteristics of the family that are easy to regard as irrational. Money is important; to pretend otherwise is to ignore the world in which the family of the developmentally disabled child exists. Consider what follows then as an exploration of just how important money might be, revealed by the empirical adequacy of the model. Not to consider money is to consider a distorted representation of the world.

Economics is the study of the allocation of scarce resources. If resources were not scarce, there would be no need for systems of allocation; everybody could take as much as he or she wanted. But the world does not work like the Big Rock Candy Mountain. Most resources are scarce; some, like time, would be scarce in any conceivable social system; some, like clean air, water and nature, though once plentiful, are now becoming scarce and hence subject to economic analysis.

Economics , though it may be a dismal science, presupposes rationality in the behavior of economic units. Frequently, the other ways in which we look at handicapped children and their families assume irrationalities even in economic behavior. Therefore, if an economic model of family, with the necessary assumption of economic rationality, is able to account for much of the behavior of the family with a handicapped child, it will, in addition to leading to policy consequences, imply that families of handicapped children are economically rational. To consider them, at least economically, as irrational, runs counter to the evidence.

The unit of economic analysis can be the individual, the firm, the nation, the family, etc. Recently, by attending to nonmarket, "shadow" prices, economics has entered the realms of social and family decision-making. Economically, the family seeks to maximize its utility rationally, under constraints given by a budget. Such maximizing behavior is part of the definition of rationality.

Though surveys have been made of family consumption patterns, they have not, unfortunately, identified the families of handicapped children. If the model presented here is reasonable, then studies identifying handicapped children are reasonable studies to conduct.

The economically rational family with access to the means of choice (easy and adequate birth control methods) will have that number of children which maximizes its utility. This utility is a function of psychic variables and of present and expected income. Without child labor, current financial income from children is zero or, more usually, negative. Expected income (potential support to the parents when they become older) is still a consideration even with Social Security payments, Medicare, and other insurance.

The costs of having children are high. Initially, the child will require the full-time attention of an adult, usually the mother, sometimes a day care center, more rarely the father. Since time can be exchanged for money, all of this costs. Further, the child may need special foods, medical care, recreation, toys and clothes, and doubtless will be a drain on other family resources as he or she wears out the living room carpet or the sleep time of the wage earner(s), and interrupts other sources of pleasure to the parents. Presumably, these costs are compensated for by the expectations of satisfaction which the parents have from the child (otherwise parents would not have as many children). Obviously, too, more than a certain amount of this disruption exceeds the expected satisfaction from children, else, given a choice, parents would nonetheless have as many children as biologically possible.

The variables in an economic model of the family are the family income; the family utility function (a function including the expected and current value of the child); current expenses, in which expenses of the child figure largely; and current and future psychic satisfactions.

Now suppose that one of the children has a handicap. This may or may not alter the psychic satisfaction in the child. Almost certainly it will affect the pecuniary variables. Currently, the disabled child will be a more expensive child; in the future, the disabled child will probably be a worse investment.

The child will be more expensive, for the handicapped child requires more time and attention and may well require more medical care, special schools, special transportation, etc. As for being a worse investment, it is likely that given the socioeconomic construction of the handicap, the structure of discrimination, the structure of the workplace, and possible—although far from sure—lower job capabilities, the handicapped child will have less expected value to the parents than will the able-bodied child. To this usually substantial degree, the disabled child will be a worse investment than the able-bodied child.

Even handicapped children who become adults can be a continual drain on the family. Not only do they not provide the family a

positive return to their investment, rather, the return may even be negative. If so, the handicapped person will be, in effect, an economic child of the family for his or her whole life. If, as the child ages, the subjective probability of his or her being a wage earner falls, the subjective expectation of the child's future value shrinks.

It is possible that much seemingly irrational parental behavior towards the disabled child can be accounted for by the rational perception that the child, given current social structure, will have less payoff and will require more investment. Given these probabilities, the economically rational family may allocate resources differently from an allocation toward an able-bodied child. There are even times (when more support can be gotten by doing so and/or when psychic displeasure is occasioned by the child) when a family may try to relieve itself of its expenses and bad investment by child abuse, by cacheing the child in a figurative closet, or by subjecting the child to other neglects. Or it may, partly for such reasons, institutionalize the child.

But the costs to the handicapped child and to society may not be the same as the costs to the family. There is economic market failure in situations in which the handicapped child suffers familial neglect, overprotection, or lack of confidence in his or her future, because society may have costs in the form of transfer payments, forgone productivity, social aesthetics, etc. In such situations, as economics has it, it is rational and reasonable for society to make economic interventions since the market by itself is not working up to snuff. Such interventions are usually referred to as "policy."

Two straightforward general policy options for the government emerge from this model. One is to make the handicapped child into a better investment. This can be done by passive antidiscrimination laws, such as sections 504, 503, and 501 of the Rehabilitation Act of 1975; by subsidizing higher educational instruction; by providing employers with tax breaks for hiring handicapped workers (like the current $25,000 deduction to make the work-place architecturally accessible, as well as wage supplements of a more general and far-reaching sort); by underwriting college expenses; or by allowing the handicapped adult tax credits for handicap-related expenses. All such measures make the future expected value of a handicapped worker substantially greater, and increase incentives to invest, particularly in human capital—a family decision which would make life easier for both the disabled child and society. When considering social investments, the government should take into account their effect not only on people already adult, but on children whose family lives are affected by their future status and investment payoff.

A second, altogether straightforward, option is to provide family subsidies. With an increased budget, the family can do better by a handicapped child, without at the same time doing worse by able-bodied children. One rational consequence, given the possiblity of disability occurring in any child not yet born, is to have a childhood disability or cash subsidy through which families would insure against the possibility of having a disabled child. This could be done

in social security-like payments or more reasonably out of general revenue.

It is reasonable that the family receive *cash* payments related to the additional expenses involved in rearing a developmentally disabled child, for usually the family is the best judge of where the money goes, will behave rationally with supplements to its income, will increase its decision-making ability, and will improve the overall quality of the family to the disabled child, beyond the goods and services allocated to the child.

Of course, instead of making cash payments, it would be possible to provide services or vouchers which could be redeemed for services for the handicapped child. The direct provision of services assumes that there are mechanisms superior to the market for deciding who is to get what, when, and how. This assumption may or may not be tenable. However, note that we do not as a rule make that assumption for people who are wealthy enough to buy whatever services they want. To increase the budget, no matter in what form, is to increase the child's chances of development, growth and happiness, but the direct provision of services diminishes family decisionmaking power compared with the same level of cash payments. Such power is important in its own right, and is to be respected and encouraged. Cash payments support the child by supporting the family, a goal at least theoretically admirable to whatever extent it is possible. Doubtless, there will be certain services which are not well provided by the market and others which, for political reasons, we might wish to supply through the government. (E.g., one could provide vouchers, government-subsidized discounts for purchases for handicapped children, or some combination of these and other policy alternatives.)

With added cash income, there will be more spent on able-bodied brothers, sisters and parents, as well as on the handicapped child. This may all be to the good, since other family members may be suffering deficits given the presence of a handicapped child. Added income may spell the difference between being forced to institutionalize the child and taking care of the child at home (coincidentally, at a lower cost to the government). Added income can buy time, by substituting services on the market for services provided by the parents. It can buy sanity for the parents, providing money for babysitters, movies, and outings once in a while. There are many uses for added income, and society, acting on behalf of the handicapped child and his or her family as well as on its own behalf, has reason to see that the family of the handicapped child gets such added income.

One might want to see more spent on the handicapped child. Parents will spend more money, more time, more attention on the child if it makes sense to; i.e., if the handicapped child becomes a more attractive investment, through assured future employment, schooling, marriage, and entry into the world, in short, into adulthood. The current separation of the future from the childhood of developmentally disabled children is a disgraceful one, profoundly

debilitating to the child and deeply inefficient for society. The connection between adulthood and childhood is forthright in an economic model of the family.

There are other uses to which such an economic model might be put. One could develop computer simulations of family consumption to see the effect of increased assets and the presence of developmentally disabled children on the consumption and utility of the individuals in the family. One could predict the relative expenditures on disabled versus able-bodied children, the relative human capital versus nonhuman capital expenditures, and the effects of future investment potential on current economic behavior.

All such predictions, explanations, and descriptions would be predicated on the economic rationality of the family, certainly a part of what we mean by rationality in general. If such a model proves accurate in its predictions, it may cause us to revise some of our current notions of the behavior of families with developmentally disabled children, notions which do not assume rationality. Further, it has the virtue of leading to direct and simple policy consequences.

Of course, this economic model, particularly as presented, is an oversimplification. And yet, with certain improvements and formalizations, I would submit that it is not all that much of an oversimplification, and certainly less of an oversimplification as regards the not-insubstantial pecuniary variables in developmental disability. If it is not an over-simplified model it should be attended to with at least the respect that we give to other accounts of the child and the family, and its policy implications should and can be taken seriously. Finally, the starkness and brutality of this model should be recognized, not as part of the model, but as part of the situation of developmentally disabled children and their families in our society.

It is not easy to be a developmentally disabled child, nor to be the parent or sibling of a developmentally disabled child. The economic model of the family of the developmentally disabled child spells out what we mean by not easy, measures it, and exposes it to policy manipulations such as childhood disability insurance, equal opportunity laws, and mainstreaming. . . . public policy.

ECONOMIC FACTORS IN FAMILY CARE

Elizabeth M. Boggs

Economics has been defined as the science of allocating scarce resources. With equivalent accuracy, politics could be defined as the art of distributing costs. In the making of public policy, economics and politics are usually inextricably intertwined. Certainly they are intertwined in the espousal of deinstitutionalization which, in turn, triggers our consideration here of public policies "facilitating family care of developmentally disabled members."

Economists study the traffic in "goods and services." To the layman, "goods" is a kind of collective noun for tangible commodities (as in "dry goods") but some economists use "goods" as the plural of "good," a good being shorthand for "a good thing." The good may be tangible, such as an ice cream cone or an habitable house, or intangible, such as a beautiful view, enjoyment of a symphony or a sense of accomplishment. After all, people pay good money for such things.

Thus far in this conference we have not squarely faced the issue of whether "family care" is a universal good. If it is not universally good, then when is it a good, and how good is it? If public policy is to support family care of a disabled member, allocating scarce resources to family care and distributing the costs among individuals and groups in our society, then we must show that it has a social value.

Since our espousal of family care is related to our endorsement of normalization, I'd like to use *normalization* as a point of departure by asking under what circumstances family care of a nondisabled family member is valued in our society and then asking how this schema might change when the member is developmentally disabled. Generally, we think that family care is good for children up to around age 18, at which age, in our times, children tend to fly the coop, join the military, go away to college or begin supporting themselves and establishing their own households. Whereas the move out of the parental home was in earlier generations triggered by marriage, today even the unattached "depopulate." It should be noted, however, that there is a substantial number of non-handicapped children, even young ones, for whom continuing care in the natural or adoptive family is, for one reason or another, not feasible or desirable. Thus, public policy permits alternative arrangements as well as accommodation of numerous variants on the prototypic family, such as one-parent families, family communes, and small congregate units, particularly for adolescents.

It is also socially acceptable for a nuclear family to continue to house an unmarried adult member; however, this practice is much

less common than it used to be, even though, until quite recently, there was considerable pressure on families to maintain such a member if he or she were disabled. As late as 1972, federal welfare laws permitted families to be held liable for the support of an adult disabled child, even though the same family could not be held liable for the support of an adult daughter who herself had a legitimate or illegitimate child. Enactment of SSI was a major step in public policy in this and other respects.

Without examining this issue further, I want to state several premises which will serve to focus our analysis of economic factors on a set of considerations that are manageable in the time available.

1. Handicapped children can and do benefit from family care in natural, adoptive, and foster homes for the same reasons, and under somewhat the same circumstances, as normal children. As a corollary, the same reasons for out-of-home care for some children may be operative for handicapped children; additionally, there may be special circumstances related to the handicapped, and not readily amenable to remediation, which would justify out-of-home placement for some handicapped children. The presumption, therefore, should be in favor of care in the natural (biological) home, but it is a rebuttable presumption.
2. There should be no presumption that a handicapped adult should remain in the parental home, although neither public policy nor public mores should place obstacles in the way of this arrangement if it is satisfactory and beneficial to the parties involved. In short, public policy should be neutral on this score and supportive of choice. The same rule should apply to other types of non-nuclear memberships.
3. Family care should be considered successful when it:
   a) is tolerated by the family without major psychic costs to the parents or siblings; and
   b) is at least as beneficial to the handicapped member as some alternative care.
4. While a number of innovative and socially useful observations might be directed to facilitating "head of household" or spousal roles for adult developmentally disabled members or a nuclear family, these observations are sufficiently different from those for filial relationships as to require separate examination. Moreover, these roles will be more readily assumed in the future by developmentally disabled persons if family care is more secure for them as children today.
5. Although the proportion of persons under age 22 both in resident populations of (public) institutions and in admissions cohorts has declined significantly in the last decade, it is still true that two out of every three persons admitted is under 22; therefore, preventing or deferring admissions of children is still an important strategy in reducing the population of institutions. (Scheerenberger, 1976). Moreover, there is evidence to support the view that prevention of institutionalization on a case-by-case basis is

less costly in both psychic and cash costs than later deinstitutionalization.

For these reasons I will direct the rest of my discussion of economic factors primarily to those which have an impact on the family while the disabled member is a child. Even with this limitation, a number of variables may enter. A proper public policy development strategy should incorporate a "market analysis," in which specific target populations are identified and their particular needs and interests are pin-pointed. It is well known that the age of a child, the severity of handicap, the socio-economic status of family, ethnicity and a host of other factors have bearing on what families of developmentally disabled persons need and want and, hence, what they find "facilitating." What follows can only set the stage for such needed analyses.

The Economic Matrix

When economists discuss the allocation of scarce resources, they do so in several dimensions. It is not merely a matter of deciding who does or does not get heating gas in a cold spell or of choosing between building a destroyer or running a thousand day-care centers for a year. There are ripple effects of each such choice. Ship construction creates one kind of job in one place; day care generates employment of another kind. Moreover, certain combinations of expenditures are more efficient than others. For example, if one wishes to produce the most bread possible for $10 one must buy the ingredients in the right proportions, allocating one's limited resources (dollars) among the flour, milk, yeast, shortening, etc. None can be omitted regardless of unit cost. This analogy is familiar to the family who must purchase a mix of food and shoes and heat and fuel, and who also must see that each member shares in the family commons according to his or her own needs.

The economics of the family is, however, not limited to spending the family's cash income or trying to augment it. First, we must recognize that, to an increasing degree, families are in a position to draw benefits from society. Our universal free public schools are only a little more than a century old, yet they clearly are a major economic contribution. Many of our ideas are changing about what ought to be personal and intrafamilial liabilities, and which familial costs (and more specifically child rearing costs) should be subsidized in some way by society. Public parks, Boy Scout troops, day care and libraries are among the components which are made widely available to families either through government or through societal enterprises, such as the United Way.

Secondly, it is necessary to consider all the productive work that is done within the family and by its members for its benefit regardless of whether that work is recognized through a pay-check. Culley, Van Name and Settles (1976) have given us an excellent summary of the direct and indirect costs of child raising. The direct out-of-pocket costs of raising the first (normal) child from birth to age 18 have been variously estimated to fall in the range of $50,000

to $100,000, but these figures triple when indirect costs are taken into account. Indirect costs refer to the value of the time spent by parents in child care and additional household tasks (such as added laundry) as well as "opportunity costs" i.e., loss of earnings by the care-taking parent who could have been otherwise employed. When both parents work (but do not pay for child care), the combined amount of time invested by them in child care and household tasks decline but this is partially compensated for by their expenditures for labor-saving devices, convenience foods, eating out, etc. It might be added that family members are estimated to invest three or four times as much time each day in caring for an infant than a ten year old. Part of this difference is accounted for by the caring activities of the school, which is a societal contribution. It should also be added that there are some contributions to child care and child rearing by persons who are not members of the nuclear family, such as neighbors, extended family members, and "helping networks" (Collins & Pancoast, 1976).

Finally, it is important to note that there are intangibles with economic value to be considered, i.e., psychic benefits and psychic costs. They are part of the mix, like salt in the bread recipe. There is a limited and imperfect convertibility between psychic and tangible (cash) benefits; for example, most juries will award substantial dollar damages for pain and suffering for an auto accident victim. Children cost, in cash and, while their labor may at one time have seemed to balance out this cost, today it is apparent that people who have children because they want them are counting the psychic benefits, which may compensate for the dollar outlays.

As Dr. Roth has pointed out, most families do behave as rational economic units; they attempt to allocate their resources so as to maximize their well being in regard to both subsistence and satisfactions. They and others on their behalf also distribute the costs among various payors. These two dimensions can be related through construction of a matrix as in Figure 1. Vertically we display the various goods for which outlays are to be incurred; horizontally we distribute the cost of each type of good among various payors, including those who contribute unremunerated labor. In this diagram, for example, C-42 represents the value of do-it-yourself repairs to the home.

It is often easy to overlook the fact that several payors may contribute to making a single type of commodity or service available to the family. For example, although the family is primarily responsible for buying food with cash, a contribution may be made to this total by a school lunch program, or the family may raise some produce, in which case they are paying in-kind, in labor rather than in cash at the supermarket. Rushmerhas (1975) has pointed out that a large portion of health care is self-care or intrafamilial care.

If, in Figure 1, we sum across by rows we can calculate the costs of a particular type of expense when the contributions of all payors are taken into account; if we sum vertically by column, we get the total cost borne by each payor separately. It is obvious that there will

be different distribution patterns for different families, and that, while families exercise only limited control, shifts can be made within the family. There is something of an ongoing game among families, public agencies and legislative bodies, each trying to lay off some costs on the others. The school may want the family (through its health insurance) to pay for setting a bone broken in football practice; the county may want the state to subsidize a county bus system so that families won't be required to pay higher fares; the family may want the municipal planning board to zone against industry in the valley so that family members can enjoy the psychic benefits of a view of the mountains and the health benefits of clean air; states may want the federal government to pay the costs of welfare programs, and so on.

Because of the public interest in having future citizens cared for, maintained and educated through what appears to be the most effective social institution yet devised for the purpose, public policy is directed toward enhancing family life. To do so, public policy development must address its ability to influence the family's choice within this matrix so that the well-being of children is maintained at acceptable standards or maximized. Many people feel that the country is divided, or at least confused, about what public policies affecting the family should be at the macropolicy level and for families in general (Rice, 1975). This being the case, it is difficult to derive a set of variant "public policies for families with disabled members," especially one which will be "normalized," since the norms themselves lack consensual support. However, there is wide agreement that (1) some of our present policies, notably those in welfare, are not constructive, and (2) cash isn't the only thing families need.

As Mary J. McCormick points out in a book aptly called *Enduring Values in a Changing Society* (1975), public policy toward persons who are economically dependent has been molded by a definition of poverty as "a lack of income needed to acquire the minimum necessities of life." She pleads for a view of poverty "within the context of society as a whole—political, cultural, and social, as well as economic, financial, and individual"—leading to an emphasis on "supporting a desired level of well-being," which goes beyond (but is not necessarily more expensive than) "subsistence . . ." Such goals require a combination of strategies. For example, in its study of families, the Carnegie Council placed major emphasis on the obvious need to assure that families have enough cash income to secure the basic necessities for their children, but concurrently recommended that public policy be directed to restoring to families an important psychic benefit, i.e., the sense that they have authority, competence, and range of options to make those decisions for the benefit of their children which are commensurate with the responsibility for which society holds them to account (Keniston, 1978). Effectuating this recommendation may require more subtlety than discrete public programs can command. An experiment in giving parents education vouchers was expected to

enhance parental command of education through offering a choice in schools; thus far it appears to have had a mixed reception (Cohen & Farrar, 1977).

Impact of Childhood Disability on the Family

All of the foregoing is clearly applicable with special force to families with disabled children. There is little doubt that the care of a handicapped member within a family costs more in cold cash than it would if the member had no handicap. Whether these out-of-pocket costs are clear or concealed, high or modest, borne by the family directly or by "society" in its myriad forms, they represent a price society pays for its lack of success in the field of prevention.

These and other costs can be added into the matrix represented in Figure 1, either by increasing the appropriate matrix elements (e.g., increasing cost of raw food for a child on a PKU diet) or by adding some new items to the list of goods to be purchased. (See Figure 1: Extraordinary Expenditures.) Separating out extraordinary costs can help us to pin-point the points of stress most amenable to alleviation. For example, if child-care of an infant takes 5 hours a day, but child-care of a normal ten year old only 1½, we should identify as extraordinary 4½ of the 6 hours a day which may be required by a physically helpless ten year old, or by a mentally retarded ten year old whose high mobility combined with disregard for personal danger requires continuous supervision. Relatively little has been done to measure these differential or extraordinary costs, many of which are not out-of-pocket but in-kind or psychic. In any case, they are highly variable from family to family, so that averages, even if we had them, could be misleading.

Once again, we come face to face with the fact that accountable cash costs do not usually measure the extra psychic or other indirect costs (particularly those having an impact on other members of the family) including "opportunity costs," i.e., what would have been done if resources (psychic or otherwise) had been differently used. How many fathers have turned down a promotion because it would have meant moving the family to a community that appeared less hospitable to the handicapped child? There is research to indicate that, given the same criteria of socio-economic status and education, families of retarded children are less upwardly mobile than others. There is a dollar (and productivity) cost to society and to the family, and an additional psychic cost to the head of the family.

Having read for the second time the descriptions by Michael Bayley (1973) of "structures for coping" developed by families in Sheffield, England who maintained a "severely subnormal" son or daughter at home beyond age sixteen, I am deeply impressed with the constriction of human potential experienced by parents, especially mothers, in these families where the need for constant care is a pervasive fact of everyday life. England provides a "constant attendant allowance" for families who care for a severely disabled child. This cash allowance is not means-tested nor tied to receipt of

TYPES OF EXPENDITURE	SOURCES OF SUPPORT								
	1. Family Cash Income	2. Family In-Kind Income	3. Extended Family	4. Neighbors	5. Philanthropy	6. Municipal Government	7. County Government	8. State Government	9. Federal Government
1. Raw Food	C_{1-1}	C_{1-2}	C_{1-3}	C_{1-4}	C_{1-5}	C_{1-6}	C_{1-7}	C_{1-8}	C_{1-9}
2. Food Preparation	C_{2-1}	C_{2-2}	C_{2-3}	C_{2-4}	C_{2-5}	C_{2-6}	C_{2-7}	C_{2-8}	C_{2-9}
3. Shelter	C_{3-1}	C_{3-2}	C_{3-3}	C_{3-4}	C_{3-5}	C_{3-6}	C_{3-7}	C_{3-8}	C_{3-9}
4. Home Maintenance	C_{4-1}	C_{4-2}	C_{4-3}	C_{4-4}	C_{4-5}	C_{4-6}	C_{4-7}	C_{4-8}	C_{4-9}
5. Clothing	C_{5-1}	C_{5-2}	C_{5-3}	C_{5-4}	C_{5-5}	C_{5-6}	C_{5-7}	C_{5-8}	C_{5-9}
6. Physical Care of Child	C_{6-1}	C_{6-2}	C_{6-3}	C_{6-4}	C_{6-5}	C_{6-6}	C_{6-7}	C_{6-8}	C_{6-9}
7. Supervision of Child	C_{7-1}	C_{7-2}	C_{7-3}	C_{7-4}	C_{7-5}	C_{7-6}	C_{7-7}	C_{7-8}	C_{7-9}
8. Education of Child	C_{8-1}	C_{8-2}	C_{8-3}	C_{8-4}	C_{8-5}	C_{8-6}	C_{8-7}	C_{8-8}	C_{8-9}
9. Health Care	C_{9-1}	C_{9-2}	C_{9-3}	C_{9-4}	C_{9-5}	C_{9-6}	C_{9-7}	C_{9-8}	C_{9-9}
10. Transportation	C_{10-1}	C_{10-2}	C_{10-3}	C_{10-4}	C_{10-5}	C_{10-6}	C_{10-7}	C_{10-8}	C_{10-9}
11. Recreation	C_{11-1}	C_{11-2}	C_{11-3}	C_{11-4}	C_{11-5}	C_{11-6}	C_{11-7}	C_{11-8}	C_{11-9}
12. Special Supervision	C_{12-1}	C_{12-2}	C_{12-3}	C_{12-4}	C_{12-5}	C_{12-6}	C_{12-7}	C_{12-8}	C_{12-9}
13. Home Therapy	C_{13-1}	C_{13-2}	C_{13-3}	C_{13-4}	C_{13-5}	C_{13-6}	C_{13-7}	C_{13-8}	C_{13-9}
14. Special Devices	C_{14-1}	C_{14-2}	C_{14-3}	C_{14-4}	C_{14-5}	C_{14-6}	C_{14-7}	C_{14-8}	C_{14-9}
15. Home Training	C_{15-1}	C_{15-2}	C_{15-3}	C_{15-4}	C_{15-5}	C_{15-6}	C_{15-7}	C_{15-8}	C_{15-9}
16. Advocacy	C_{16-1}	C_{16-2}	C_{16-3}	C_{16-4}	C_{16-5}	C_{16-6}	C_{16-7}	C_{16-8}	C_{16-9}
17. Adaptation of Home	C_{17-1}	C_{17-2}	C_{17-3}	C_{17-4}	C_{17-5}	C_{17-6}	C_{17-7}	C_{17-8}	C_{17-9}
18. Escort Service	C_{18-1}	C_{18-2}	C_{18-3}	C_{18-4}	C_{18-5}	C_{18-6}	C_{18-7}	C_{18-8}	C_{18-9}
19. Extra Insurance	C_{19-1}	C_{19-2}	C_{19-3}	C_{19-4}	C_{19-5}	C_{19-6}	C_{19-7}	C_{19-8}	C_{19-9}

Figure 1

Distribution of family expenditures, ordinary (1-11) and extraordinary (12-19), by source of support.

any professional service. In addition, there is a well-established system of local "mental welfare visitors." Yet even these provisions did not suffice to liberate these families or, for that matter, their handicapped members. The investigator, Michael Bayley, concluded that the formal paid-for help given by the social workers, even in home visits, was relatively ineffectual in dealing with "the daily grind." Bayley considers that such help as was received was most effective when *near at hand, frequent, reliable, punctual and regular.* With the exception of daily day care (a form of respite care), the most useful forms of assistance were likely to be informal and neighborly, or within a kinship network. (Rice [1977] has noted that, although extended families no longer live under one roof, they still exist as social entities and that, with cars and telephones, they continue their mutual support functions.)

Some of these findings remind one of the studies done by Maslach (1978) on "burn-out" of direct contact professionals and paraprofessionals such as child care workers. Burn-out can be alleviated by interspersing direct contact with other useful work several times a day and by arranging weekly to monthly "rap sessions" among peers. These findings clearly carry over to parents, for whom an improved quality of life will surely "facilitate family care." Must it be that the most burdened are least often able to participate in "parent groups?" Why is respite care so often seen in terms of a two week annual vacation? Group home parents who are subject to burn-out may resign; natural families cannot resign, a factor which adds to their sense of being victimized. The fact that some middle-income families pay so painfully for private care of severely handicapped children indicates the dollar value they place on what they buy for themselves (as well as for their children) when they choose care away from home. In a study on the elderly in Massachusetts (Sager, 1977), it became apparent that about half the families were unwilling to take a chronically disabled person back home from the hospital even when supporting services were promised. This was especially true where the patient was *less* elderly. The evidence seems to be that "no end in sight" is demoralizing. This is one reason why I favor public policies which make it respectable to contemplate that one's son or daughter will eventually move away from home even if disabled. There has recently been a spate of writings on cost benefit analysis and other approaches to the economics of "alternative living arrangements." (Intagliata, Willer & Cooley, 1978; Jones & Jones, 1976).

Some compare group homes with institutions and family homes. If one counts the labor of family members who give care and supervision as one would count and pay for it if it were given to another as a provider, the alleged economics of care in the natural family are much less striking. Where home care of the elderly, which includes the cost of personal care, is nevertheless found less costly than institutional care, it is usually because more care than necessary is made available in the institution (Sager, 1977).

Recognizing true economic costs should make us less reluctant to pay for services rendered in the home. On the other hand, as now delivered, supporting services in the home are often overorganized or overprofessionalized when (as rarely) they are available. A young woman who is physically handicapped but attempting to live as independently as possible wrote to Senator Dole describing what her home health aid does for her (Doyle, 1978). The young woman herself, although college-educated, works for the minimum wage; the aide is paid $7.25 a hour under Medicaid. A little of the aide's time is spent rebandaging and bathing, much is spent doing laundry, placing food within reach in the kitchen, and removing stockings which the handicapped woman cannot take off by herself. What is "health care?" That is a multi-billion dollar question. Politically, it is almost certain that any provisions paid for out of a public "medical" pocket under national health insurance will require licensed or at least professionally supervised personal care, with all sorts of overhead costs laid on as a result. Indeed, we do need official, qualified, certified, homemakers and home health aides in greater supply, but salvation will not lie in that alone. As already mentioned, a great part of the health care most of us receive is, in fact, self-care or intrafamilial care. Defining *any* personal service done for a person because he is disabled as "health care" may boomerang. We have to be more ingenious in capitalizing on the golden egg of "home potential" without killing the goose.

In the last several years a number of writings have put new emphasis on two themes which seem most pertinent in context of psychic and in-kind benefits needed especially by families of the handicapped. First, there are the discussions of "helping networks," i.e., informal relationships among people who provide mutual support and help (both instrumental and affective) spontaneously and by informal barter (Caplan & Killier, 1976; Collins & Pancoast, 1976; Sarason, Carroll, Maton, Cohen & Lorentz, 1977). These are not the same as "self-help" groups, although some self-help groups do perform network functions, particularly those true self-help groups which are not managed by professionals (e.g., the National Society for Autistic Children chapters or local units of the National Association for Retarded Citizens in the fifties). The informal support and networking idea is beginning to catch on. It is reflected in the leading recommendation of the President's Commission on Mental Health, as well as in repeated allusions by Mrs. Carter both before and after the report was issued (President's Commission on Mental Health, 1978).

The second theme has to do with important psychic benefits which some psychologists call "dominance," or "internal locus of control." This concept refers to our need to feel that we have some control over our destiny; that what we choose to do, or not do, makes a difference in our own lives (Mehrabian, 1976). Obviously we need to enhance dominance for handicapped persons, including retarded persons, but we should not neglect empowerment for their

parents also. The Keniston (1977) report (Carnegie Council study on families), inadequate as it is in dealing with handicapped children, emphasizes a need for returning "power to parents" generally. In many respects professionals and societal mechanisms, including the courts, are usurping the parental authority making parental responsibility possible. Again, this problem is accentuated in families of the handicapped. The Hobbs report, *The Futures of Children* (1974), as well as the Rand report (Kakalik, Brewer, Dougharty, Fleischauer, Genensky & Wallen, 1974), specifically supported "empowerment of parents" of the handicapped. Empowerment, however, is not so much a matter of "rights" as an infusion of capacity. The mandated right of parents to participate in the individual educational plans of their children may have, on balance, destroyed more parental "dominance" than it has engendered.

"Cashing out" benefits as a method of restoring autonomy may be overvalued, unless dollars can be translated into something else perceived as critical. In a survey of families whose child had already been institutionalized, five out of twelve families gave as a main reason for the decision to institutionalize that the retarded child "had to be watched and looked after more carefully" while only one in twelve found home care too costly (Frohlich, 1975). Even poor families in rural Alabama whose children lived at home reported the extra costs as but one negative factor, along with inconvenience of various kinds (Dunlap,1976). In a study of family care providers in New York State, Intagliata (1978) found that only 8% cited a need for extra money as a motive for accepting a retarded person into the home and, indeed, more than 60% had incomes over $10,000. They reported that the major problem was the amount of care and supervision they were required to give, even though the majority of residents were only mildly or moderately retarded. Although social workers working with foster families (in a generic foster care program) expected families to be motivated by lower level needs, such as psychological well-being and security, a research team found that parents thought in terms of "high level needs" such as personal esteem and self-actualization (Settles, Culley & Van Name, 1977).

In order to understand the implications of such findings for public policy, it is necessary to consider the conversion of economic (dollar) factors into psychic or motivational factors and vice versa. This we might represent schematically as Figure 2. In this diagram the heavy lines represent putative major exchanges, the lighter ones positive but lesser exchanges between the economic (left) side and psychic (right) side. The left side represents those things that can be generated by a willing and responsive community, guided by "public policy"; the right side represents familial responses, which may express themselves as tangible actions on behalf of the nandicapped member. The crosswalk between the two sides is by no means unencumbered and the flow is not free or entirely reciprocal, but the channels are those that must be used if the family is to be the vehicle for achieving social goals.

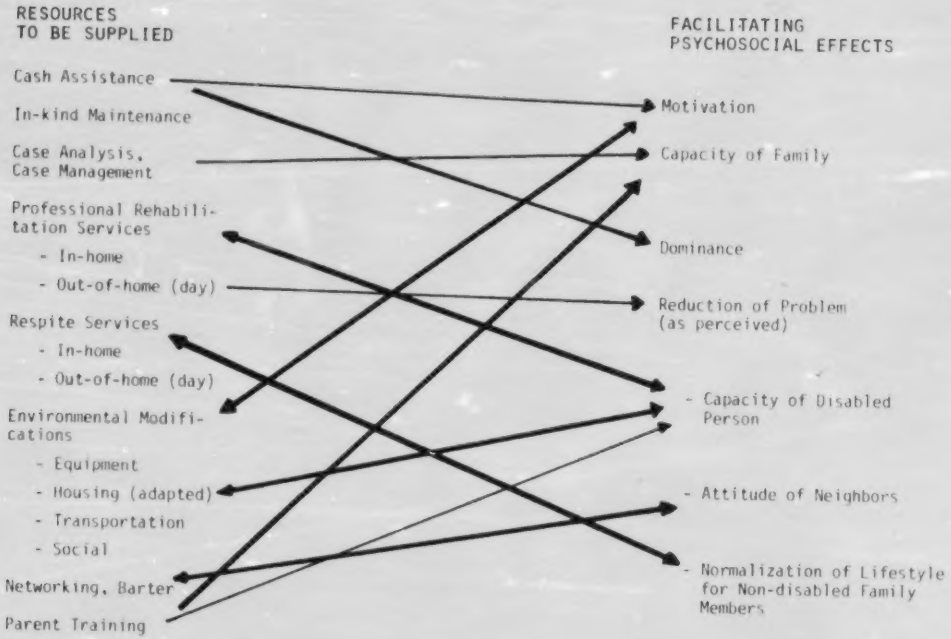

Figure 2

Schematic representation of the conversion of economic factors into psychic or motivational factors and vice versa.

From an economic or "marketing" point of view, the mix of resources to be selected from the left column which will have the effect of maximizing an "x" composed of a combination of factors in the right hand column (always given the constraint that the total investment is limited in some way) will be different for different families in different circumstances. For example, cash assistance such as SSI may be critical to capacitating a family which is marginally "poor," but have little effect on either the capacity or motivation of a well-to-do family, especially if what they most need (e.g., parent training) is not available in the marketplace.

As pointed out by Dr. Horejsi, "discomfort" is a powerful negative motivator. In a recent meeting I heard one parent of a six-year-old say, "Even if you paid me $12,000, I would not change my mind about placing my child in a good residential school." Another parent was clearly "turned off" by the idea that professional services would be brought to her *in her own home*. Reading between the lines, she saw this as an invasion of privacy; she might have been more accepting of day training in a center. Similarly, there are families whose adult members never get a full night's uninterrupted rest; their first priority is *not* training in language development. Dr. Nanette Doernberg (1978) of the Einstein College of Medicine in New York has pointed out that the way in which some health and education services are delivered to children actually exacerbates the family situation. For example, daytime appointments further alienate fathers; expecting a busy mother to add an extra hour a day of therapeutic exercises just deprives her non-handicapped children of her attention.

All this is not to say that cash payments have no place. In a study of foster care in which foster parents were paid for their services as well as for the costs of the child's maintenance, a new resource of foster families was uncovered among those in which the income of the mother was an important factor in life style (Jaffe & Kline, 1970). And, of course, as services that are desired become available for purchase by the family, the use of a cash stipend which the parent can spend as he or she chooses cannot help but contribute to "dominance," as well as to alleviating the specific problem.

It is in part for this reason that NARC and other disability consumer organizations have been pushing for an additional "attendance allowance" as part of the SSI benefit to be paid to those eligible children and adults whose disability is so severe as to require personal care and/or supervision on a daily or near daily basis, regardless of whether the individual may also work. Such allowances are available to disabled adults in all developed countries except the United States, usually without a means test, in the manner of Social Security. In a dozen or so countries, such allowances are also available without a means test to families of disabled children cared for at home. The rationale for these payments is to provide compensation for the extra effort in care, the "opportunity costs" (Sterner, 1976). It is reported that there is also a psychic dividend; families feel that society values what they do. Thus far the

United States has, in effect, taken this step only for very low income families by establishing SSI for children at a rate somewhat higher than Aid to Families with Dependent Children, and including intact families as well as one-parent families.

Distinguishing between "ordinary" costs and "extraordinary" costs associated with a disability is easier in principle than in practice. However, as parents respond to social policies which are targeted on fairness, even if they are more symbolic than real, the potential difficulties in quantifying compensatory programs should not preclude making the effort. In particular, there should be greater fairness in respect to allocation of the costs of basic maintenance. Parents of minor children who are handicapped should bear the costs of basic support (in-home or out-of-home) to the extent that they would be liable for a non-handicapped child. This is contradicted at present by some state laws (reinforced by SSI) giving free care outside the home, and by recent rulings interpreting the Education of All Handicapped Children Act, in which a child who is placed in a residential school setting for "educational reasons" is entirely supported at public expense, while parents of a child who is placed for "other" reasons get free tuition but may be required to pay for board. A fine and fair line must be drawn between public policies which give parents a sense that society cares and is mitigating their catastrophe, and those which invite parents to use their child to exploit the system, and even to perpetuate his dependence because of the entitlements that go with it.

Finally, it would appear that an ounce of prevention is worth a pound of cure. Offering the right amount of the right help at the right time may change a life trajectory. The "right time" frequently includes the time of crisis at discovery, and also the time *before* a family situation reaches the stage where a decision toward out-of-home placement has been formulated. Salesmen know that once the decision has been made to buy a Datsun the chances of getting the family to switch to a Pinto are drastically reduced.

In any case, the amount of research reported relative to what families really want or need at various stages in the life cycle of the handicapped member appears to be sparse. However, the following factors do recur in such studies as have been made:

—sense of social isolation, accentuated by limits on visits, free time, recreation, etc. for family members,
—difficulties with physical managment (lifting, bathing, etc.),
—interruptions of family sleep,
—time consumed in personal care, feeding, etc.,
—difficulties getting the shopping done,
—handling hyperactivity and "difficult" behavior,
—attitudes of neighbors and kin,
—cumulative effect of small harrassments,
—sense of no prospect for change/worries about the future,

—limitations on family's options in career choice, housing, locale, etc.,

—stigma,

—extra costs.

In summary the following strategies as applied to individual families are candidates for resource allocation within a public policy for facilitating family care in natural, adoptive and foster families. They should be selected and juxtaposed synergistically.

1. Early crisis intervention at the time of discovery, followed by in-home supports for very young children, including employment of parents through supportive case management, information and referral, and parent effectiveness training as applied to the disability.
2. Day care, whether it takes the form of attendance at school, attendance at a workshop or activity center, or possibly in-home day care while family members are working or otherwise out of home.
3. Other respite care with emphasis on frequency, demand responsiveness, and reliability.
4. Provision of efficient equipment and adapted housing.
5. Emphasis on skills in activities of daily living in school and other formal habilitation settings, to make disabled child less dependent.
6. Exploration and development of "networking" support systems, including identification of natural neighborhoods.
7. Cash assistance, including an extra allowance for children and adults who require extraordinary personal care and assistance with activities of daily living, or extended social supervision.
8. Coverage of extraordinary medical costs.
9. Client-oriented case coordination which is reliable, sensitive, prescriptive and has continuity.
10. Equity to all the parties involved.

ALLOCATION OF RESOURCES FOR FAMILY CARE

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Although the specific focus of this conference is the topic of families caring for developmentally disabled members, the economic issues are better understood within the broader context of policies related to the disabled or handicapped in general. Moreover, since previous speakers have discussed in some detail the financial stresses most families are experiencing when they decide to provide care rather than transfer this responsibility to other social institutions, it would seem to be more useful to touch on a number of other economic issues that have significant implications for these families, as well as the professionals concerned with their problems. For these reasons, I have organized my comments around the more generic problems of the allocation of resources and the ever present competition among human service agencies and professionals for these scarce resources.

My concern and your concern is for those families with developmentally disabled members. In a sense, we are advocates for these families. We are concerned about them, we are interested in their needs being met. This concern or advocacy is not one, however, that can be isolated from the larger issue of resources to meet the needs of all families with handicapped members, regardless of the type of handicapping condition. If we hope to identify policies that would be supportive to them, these recommendations must be realistic and feasible. To ignore the reality of their interdependence would be dysfunctional. Given the American pattern of decision-making, we are in competition with groups concerned with other handicapped persons. Even within the area of the developmentally disabled, those of us interested in supporting families are competing with those who are attempting to develop high quality institutional programs.

This concern about resource allocation decisions has a number of parts. First is the level of current and proposed expenditures. Given the problem, how adequate are they? Do they reflect a real commitment on the part of society? If we can answer this, we then need to assess the translation of these resources into programs and services. It is never a simple matter of expenditures; the ultimate quality of programs is as important. Beyond these issues, we need to examine very carefully the implicit and explicit intent of these policies and programs. What objectives are they trying to achieve? Do they support families or are they designed to encourage families (implicitly) to transfer the caring function by emphasizing substitute

services? Finally, we need to determine the target populations, the actual users, and the potential users. Are certain groups excluded in practice? While some services are universal, i.e., available to all who have a demonstrated need, others are means-tested and exclude those with incomes are determined to be too high even though they have a need for the service. In some programs consumers are labelled implicitly as good or bad, worthy or unworthy. For years, vocational rehabilitation services were denied those who were high risk in terms of their potential for employment. A major criterion for selection was the likelihood of success for the smallest amount of investment. In manpower programs this is known as "creaming." It is conceivable that a respite care program might exclude families with multiple-handicapped children or children with behavioral problems because they are more difficult to handle. All of these issues—the level of the commitment (resources); the specific types of policies, programs, and services; the implicit and explicit purpose of the services; and the target populations—are issues germane to decisions on resource allocation.

We would like to believe that decisions are rationally made. We would like to believe that the criteria used by the decision-makers are reasonable, clearly thought through, and likely to be agreed upon by most people, consumers as well as professionals. We also would like to believe that decisions are made in the best interest of the disabled person, his or her family if they are providing care, and of society in general and the state in particular in so far as it is responsible for choosing how resources are to be used. In terms of opportunity costs, once expenditures are made to achieve some good, other choices are forfeited. And finally, we would like to believe that behavioral and social scientists, human service professionals, and consumers participate in this process of decision-making.

However, neither the policy makers nor the professionals concerned with services for the disabled are this rational. This, in turn, has produced some questionable policies and practices that have created tensions in the general system. For those reasons, it becomes important to step back and examine more closely these macro-issues before looking specifically at the micro-issue of family care. As mentioned above, those concerned with the developmentally disabled are competing with others for resources allocated to the handicapped and, even within the narrower field, there is fierce competition about the use of developmental disability resources: Should they be allocated for improving institutions, developing community care services, or supporting families?

Macro-Issues: Resource Allocation and Competition

The social, economic, physical and emotional care of the disabled is and will continue to be a growth industry in this society. The prevalence of disabilities is increasing and will continue to grow at an accelerated rate over the next 25 years. It would appear that the greater our successes in overcoming the problems of infant mortal-

ity, in controlling the infectious diseases, in discovering and applying cures, drugs and techniques that have saved lives and increased longevity, the greater has been the spread of long-term disability and chronic illness. In this light, the achievements and the problems are the reverse side of the same coin—the paradox of medical and scientific progress.

In this country, aproximately 7% of the population, or 15 million people are disabled. Of these, an estimated 4 million are handicapped, and of these over 40% are severely handicapped in terms of functional ability. Who are these people? By and large, that subgroup of the population with the highest prevalence rate of disability is the aged and infirm and, within that group, those 75 years of age or older. Two of every three handicapped persons are 65 years of age or older, one of every three 75 years of age or older. Furthermore, recent projections indicate that, while the total population is expected to grow by 10 percent between 1975 and 1985, the population 65 years of age or older will increase by 17%, and those over 74 years of age by 22%. Given these trends and the likelihood that they will continue to grow over the next 25 years, we can anticipate a rapidly growing number of handicapped persons requiring health and special services. It would be an over-simplification to assume that the problems of long-term disability are primarily those of an aging population. It is important for us, though, to recognize that the greatest number are elderly persons since they are competing for resources. A sub-group of the handicapped, the severely mentally retarded, may be of special concern to us at this conference, but they are relatively small in number compared to the aged. Taking the prevalence rate of 3.5 per 1000 population, by the year 1980 there will be fewer than 800,000 so handicapped.

Given the projected increases in the population, what kind of national commitment might we anticipate? How much expansion can we hope for over the next 25 years? While it is impossible to identify current expenditures on behalf of disabled persons, some gross estimates are possible. A recent study by Berkowitz and his colleagues at Rutgers University suggests that approximately $83 billion, or 6.5% of the Gross National Product, was expended in 1973 either through transfers (41%), medical payments (36%), or direct service programs (3%). Federal expenditures represented 49% of the total; state and local expenditures, 14%; and private expenditures 37%. The researchers do point out, however, that they were unable to separate expenditures on long-term and short-term disabilities and conclude that much of these were in fact for the latter. Regardless, their findings are useful in that they show the present scale of commitment. Additionally, they report that in real terms, transfer payments increased by 47% between 1967-1973, medical payments by 49%, and total expenditures by 54%.

How realistic is it to expect that levels will be increased as the number of handicapped persons grow? What share will the developmentally disabled and their families receive? If agencies find

themselves in competition for these resources today, what might we expect in the future? In periods of economic retrenchment, agencies dealing with a particular group of handicapped persons will find themselves at a distinct disadvantage. In some instances the numbers will be small compared to others (e.g., the visually handicapped) or the specific disability will be less attractive (e.g., the alcoholic or drug abuser). Additionally, while some of the disabled and their families are well organized for lobbying efforts, others are not. Unchecked, it is conceivable to imagine a scenario in which advocates for different groups will vie with each other to prove that some disabilities are more important than others, that some handicapped persons are more worthy than others. It may be argued that children should be given priority over the elderly since their lives are just beginning; that the blind or mentally retarded should be favored over the alcoholic and the drug abuser since they themselves were not responsible for their disability; that adults should receive disproportionate amounts of resources since they can contribute to overall economic growth by working while children and the elderly are basicaily consumers. Although each group is sincere and rational in what they do, the enemy becomes "other disabled" and survival is achieved only at the expense of others.

This interpretation of the present system should not be viewed as a criticism of advocacy as such. I believe that practitioners, analysts and planners are much more effective when they are in an advocacy position, when they identify with and are sensitive to the needs of specific population groups. As opposed to the professional who gives the appearance of being detached and objective, the professional who is committed can argue for more sensitive and meaningful policies and services. But there is a danger that advocates' efforts will become fragmented and, in the long run, all handicapped people will lose. An example of this is a recent experience I had as a member of a task force connected with the President's Commission on Mental Health. In a three-day meeting a number of professionals discussed the particular needs of American families and eventually produced a series of recommendations to the Commission. Each of us had been asked to present for discussion a paper on a particular sub-group of families. Unintentionally, each of us became advocates for "our families" and attempted to demonstrate that their needs were, in fact, the most important. But whose needs were the greatest? Is it the single parent family, families with teenagers who become pregnant, families caring for the handicapped, American Indian families, black families, families headed by Vietnam War Veterans? All of these and other categories of families are at risk, but is it inevitable that, in assisting one group, we implicitly do so at the expense of others?

Historically, two fundamental criteria are introduced in setting priorities for the allocation of resources. The first is the notion of "worthy poor," a notion deeply imbedded in our long standing Poor Law tradition. Although we often tend to downplay this criterion, it has been very much a part of our process of decision-making even

in this more enlightened period of the modern welfare state. The worthy poor have, over time, included the elderly, the handicapped, and widows with children. They are worthy of assistance because they are dependent through no fault of their own. All others were held responsible for their condition; there was something deficient in their makeup. Those of us concerned with the developmentally disabled and their families fare well under this criterion.

Over the past two decades, another criterion has become the basis for setting priorities—the human investment or human capital perspective. Using benefit-cost and cost-effectiveness approaches, decisions are made on the basis of expected return for the investment of resources. Programs are compared in terms of the return (economic) for each dollar spent. We have seen this in the vocational rehabilitation effort, we are seeing it in our manpower programs. The rationale is simple and in keeping with certain basic American values. The bottom line is easy to measure—did people, as a result of the program, become independent, become producers rather than consumers, enter or return to the labor force, pay taxes and contribute to overall economic growth? This criterion is not totally congruent with the first criterion of worth vs. nonworth and, I would argue, the developmentally disabled, especially those with severe handicaps, become a lower priority. An investment in a severely retarded child will not produce the same economic return as that in a child with an orthopedic problem or in an adult handicapped through a lack of job skills. I would suggest that in times of economic retrenchment the human investment criterion becomes more commonly applied.

Recognizing these trends, a number of professionals are arguing for a more generic approach towards disability. This position assumes that a fresh look at our service delivery system would permit a more systematic consideration of alternatives which might range from better coordination among the fragmented and incomplete specialties to a more structured and generic approach to the problem. Given our negative experiences with coordination efforts (the current policy thrust), it is argued that only large-scale reorganization can be effective. Two coordination strategies are usually offered. The first involves restructuring agencies in terms of functional needs with emphasis on certain commonalities. All of the disabled have difficulty in performing the major functions considered normal for their age. They also experience financial difficulties, family stress, and a lack of social stimulation. In reorganizing the system along functional lines, high quality specialized services can be offered to all disabled persons regardless of the specific diagnosis. The alternative is to build on the growing pattern of restructuring governmental agencies into umbrella human service configurations. Although the evidence to date is not clearly positive, it is argued that the umbrella concept is appropriate. What is needed is the development of mechanisms to integrate these services at the delivery level. To date, most efforts have emphasized state-level

operations with little attention given to changing community structures.

A second concern for proponents of a generic approach is that the fragmented system has dissipated any meaningful effort for community support services that are needed by most disabled persons. While there are agencies, programs, and lobbies for the blind, the mentally retarded, children with cerebral palsy, etc., there are none for Meals on Wheels, home care, or transportation services, and expansion in these areas has suffered. A restructuring along some dimension of a generic approach would highlight these deficiencies and re-establish priorities for scarce resources. Without such an exploration, it is likely that these vital services will continue to be ignored, placing further pressures on the specialized services. In the long run, their effectiveness will be significantly reduced.

The issue of provision of generic services is controversial. While specialized knowledge and skills are essential, it does not necessarily follow that these can only be developed through categorical agencies. The provision of services specifically for the disabled or for a distinct group of disabled, tends to isolate them from other people and may deny them equal opportunity. In the past, for example, it has led to the provision of poorly paid jobs that were inappropriate to the potential of the disabled worker. Furthermore, it is interesting to note the demands by parents of mentally retarded children for admission to ordinary schools and for opportunities for their children to interact with non-handicapped children; segregation often reinforces rather than corrects negative attitudes in local communities.

The difficult question remains, however, as to how comprehensive a generic approach should be. It would be easy to destroy the effectiveness of any program by making it so comprehensive that the needs of all the disabled are included, such as housing, income maintenance, medical care, education, rehabilitation, and socialization. There are approaches between the extremes of specialized agencies and fully generic agencies and they should be examined more thoroughly. These include programs such as Triage in Connecticut, which provides comprehensive services under a single administration ranging from acute hospital care, through intermediate nursing and home nursing services, to chore and neighborhood support services. Other examples are Personal Care Organizations, Community Care Corps, and Home Care Corps, all of which are organized on relatively generic grounds. These efforts, while building on the common needs of the disabled, do not necessarily imply that all agencies be restructured to meet the functional needs of the disabled. Rather, they are building meaningful bridges with the specialized agencies by creating interfacing mechanisms. These efforts are also realistic attempts to re-examine the relationship between community support systems for the long-term disabled and institutional care. Despite the rhetoric of choice and preferences for the disabled and their families, priority (resources) has been given to institutional care. And yet, the evidence is that

most families favor home care over institutional care, that they actually are providing a supportive environment for their disabled members whether they are severely retarded children or elderly parents, and that they are doing so with little support from the organized health and welfare system.

The final issue is concerned with this country's need for a positive, integrated policy stance towards disability and the needs of the disabled. Much of the reluctance to favorably address this issue lies in the fear that when these needs and their mushrooming costs are highlighted, governments will seek ways to retrench. However, there is little evidence to support a position based on the hope that by not raising the issue, resources will be made available. The problem of financing has to be directly confronted if an adequate and effective program for disability is to be achieved. A number of alternatives should be considered and analyzed.

Insuring lifetime maintenance care for the severely disabled, in much the same way that the acute aspects of catastrophic illness are now insured, is one option. To be feasible, however, greater attention should be given to identifying populations at risk. This task is complex in that there are many technical and clinical differences related to the nature of the condition. Blind persons, retarded persons, individuals with multiple sclerosis, the quadriplegic, the severely crippled arthritic, all have different clinical requirements. There is a need to aggregate disabling conditions across diagnostic categories and yet there are not commonly used or accepted objectives of severe disability. Numerous scales measuring activities of daily living, such as the Barthel's and Pulses, measure not only functional status but also intellectual and emotional adaptability, but none are available to permit comprehensive aggregation of data. Once these aggregations are feasible, it then becomes possible to derive firmer estimates about the range of services or benefits the at-risk population is likely to require and to identify the likely utilization rate.

An approach other than full insurance would involve payment in the form of a demi-grant comparable to the disability allowance in the United Kingdom (Constant Attendance Allowance) whereby individuals identified as needing the attention of another person are given a supplementary cash allowance so that they might secure the supportive assistance they require. This allowance is not income-tested but given solely on the basis of disability.

Short of full insurance, the present Medicare and Medicaid programs could be expanded to encourage the provision of less costly and more often desirable home care services. If one chooses a non-insurance route, a variety of existing programs might be considered for expansion into more generic approaches, such as programs for the blind and crippled children. The new amendments to the Social Security Act (Title XX), which provide for personal social services, might be considered as a viable nucleus around which to construct such a system.

Regardless of the specific mechanism, whether it is the creation of a national health insurance program, some form of guaranteed income related to disability, or the large scale development of various generic supportive services, it is unlikely that such comprehensive policies can be realized unless professionals, agencies, and lay associations come together in a united front. If these organizations continue to act separately and only pressure for distinct categorical groups of disabled, these policy issues will either be ignored or receive low priority.

Micro-Issues: Families Caring for Handicapped Members

The issue of family responsibility for the care of its dependent members has, for three hundred and fifty years, been the subject of almost continuous debate. Historically, most social welfare programs were developed on the premise that the family constituted the first line of responsibility when individuals had their self-maintaining capacities impaired or threatened. It was further expected that families would support these handicapped members until the situation became overwhelming and only then would society intervene.

This approach is based on the principle that family life is and should be a private matter and, as a fragile institution, must be protected. There seems to be widespread agreement that society, through state programming, has the right to step in when individuals can no longer meet their own needs or do not have other resources to fall back on. Children who are neglected or in danger of physical abuse can be removed from their families. The isolated elderly person or the handicapped person needing considerable care and supervision can be transferred to an institutional setting. The emphasis is on the protection of the individual who might harm himself, others, or be harmed.

Intervention usually takes place after a crisis or breakdown occurs and the state's role is seen as marginal and concerned with a small proportion of the population, i.e., those who are unable or unwilling to meet their own needs through the normal mechanisms of the family and the market. Historically, then, the state has been reluctant to intervene if that intervention in any way might interfere with the family's rights and responsibilities, their privacy and self-determination.

While these principles may have shaped our social policies, there has been a growing concern on the part of professionals and practitioners that present-day families are not carrying out their responsibilities. One point of view that appears to be gaining considerable momentum is that as the state assumes more responsibility for assuring that basic social and economic needs are met (a responsibility taken on since the 'thirties), the traditional responsibility of the family to provide for the needs of its members is diminished and the family as a social institution has become less important. It has been charged that children are less inclined to

support their elderly parents and parents their handicapped children.

And yet the evidence does not support these conclusions. We are finally beginning to recognize that the overwhelming majority of handicapped people are in the community and are being cared for by their families with various degrees of support from public and voluntary agencies. It has been estimated that 7% of the population is disabled and 2.5% is handicapped. And yet, the institutional population over the past 25 years has remained fairly constant at 1%. Furthermore, it is clear that this institutional population is not made up only of the handicapped. For example, 65% of the severely handicapped are elderly and 34% are over 75 years of age. Even though the institutional rate has increased over the past 20 years (from 4% to 5%), 12% of the elderly (half of whom are over 75) or 2½ million persons, are living as dependents of their children or other relatives. If we can rely on various surveys, we must accept the fact that the majority have some handicapping condition. Furthermore, shifting to another group of the handicapped, the mentally retarded, we know that only 25% of those who are severely retarded are in institutions at any point in time. The remainder are in communities. When we look at severely retarded children, most are living with their parents.

Because of families, then, admissions to institutions of persons who are severely physically or mentally handicapped have been prevented or delayed. Many families, often with the help of friends and neighbors, have provided what can only be described as a staggering amount of care at significant social, physical and emotional costs. In this sense, the family has been a resource for the handicapped and it is becoming clearer that it has been a major resource for the social welfare system. It is frightening to think of what would happen if these families were to seek institutionalization.

However, the major emphasis in terms of expenditures is on institutional care serving a relatively small proportion of the at-risk population. Butterfield, for example, has estimated that 40% of all mental retardation expenditures are for institutional care. Of the remainder, only a small amount is used to support families caring for their severely retarded children. These families are, in fact, competing for these resources with families with moderately retarded children. Furthermore, community care cannot be equated with services supportive to families. Much of these resources are used for substitute family care, e.g., residential care facilities. In spite of this, families continue to provide care, most want to provide care, and until it is proven otherwise, we must assume that they are providing excellent care at considerable financial, social, emotional and physical costs.

The most common reason given for this emphasis on services that substitute for families, rather than support families, is that we lack sufficient resources. We must set priorities, hierarchies of need, in order to distribute scarce resources; handicapped persons

without families are at a greater risk and their needs should be met first; when, and only when, resources are increased can services be made generally available to families providing care. This rationale is simplistic for two reasons. The first is that we are never likely to reach that point when we have enough resources. The second is even more fundamental—we do not know how to support families as well as we know how to care over the caring function. Because of the way our services have been organized and the way our professionals are trained, we are fairly comfortable in substituting for families and extremely uncomfortable in supporting others who are the primary caregivers.

Professionals tend to be trained in the medical model with its emphasis on pathology. We diagnose problems, develop a treatment plan, and work toward a cure—the reversal of a perceived pathology. Furthermore, professionals are rewarded by their sponsoring agency and receive personal satisfaction when these cures are achieved. This model is clearly inappropriate for most families caring for their handicapped members, and who need support to continue. There is no pathology to be cured in these cases and, to many professionals, they are not interesting.

Even this rationale is incomplete. Preoccupation with a medical model is accompanied with a focus on individuals; most of our policies and programs define the individual as the object of intervention. Moreover, they have been developed for specific individuals, i.e., the elderly, the handicapped, children, expectant mothers, mothers without husbands, and so on. Services are provided to individuals on the implicit assumption that if an individual family member receives this service, the entire family will benefit. Although all of our social policies do affect families, the nature of the impact is basically unknown since the assumption has not been tested systematically. In practice, family members are viewed as resources (caregivers) to the handicapped person or as resources (members of the caregiving team) to the professionals. Rarely are families seen as needing resources themselves because they are providing care. In those instances when the family is the focus of the service, it more often than not has meant that professionals have defined the family as part of the problem, one of the reasons why the pathology exists.

A final reason for provision of services that substitute for family care is related to our approach to planning. It can be argued that it is technically easier to plan for services that substitute for the family rather than support it. These services lend themselves to a structured approach while family support services create all sorts of programming difficulties. For example, over the past fifteen years, heavy reliance has been placed on various national surveys. These studies have taken as the unit of analysis the handicapped individual. The data report on the characteristics of the handicapped: their capabilities and incapacities, the degree of the handicap, their socio-economic status and their living status. For planning purposes, the handicapped are then grouped by age, sex, and the severity of their condition. These data lend themselves to aggregations and a

set of programs can be developed for the sub-groups. Furthermore, handicap is usually defined in terms of the ability to carry out basic functions. How many of the handicapped are mobile, how many can bathe, feed and care for themselves? How many live alone? Given these aggregate data on the handicapped, the planner can begin to translate them into specific service plans. Needs, a vague but crucial conceptual starting point, are thus linked to an identification of tasks or functions necessary for social and physical well-being.

If the handicapped person does not have a family, or in the case of many elderly, the handicapped person lives with a spouse, the planning process is relatively straightforward. If the person is severely handicapped and needs total care, the outcome is likely to be institutionalization where the staff assumes those functions normally carried out by a family. The handicapped person is provided with a room, meals, health and personal care services, and social stimulation in a total caring environment. The residential care facility becomes the home, and the staff and other residents function as a substitute family. The planning task becomes one of estimating the number of handicapped who fall into this category and then designing the necessary services.

If the handicapped person can manage reasonably when certain functions are taken over, the task then becomes one of assessing where the individual is deficient or incapable and then providing what is necessary. Again, the available surveys are quite useful. Once norms or standards are established and functions delineated, needs can be aggregated and services designed systematically.

It is much more difficult to "plan" for those situations in which the handicapped person is living with his family, and the family has assumed the major caring responsibility. First of all, the focus has shifted from the handicapped person, a shift that is more significant than may appear on the surface. The task is no longer one of assessing an individual's capacity to function and then providing services that either totally or partially substitute for the family. What is required now is the provision of services that ease the management task of the family. If planning requires an ability to categorize need and then a capability for aggregation, the process logically begins with a search for similarities between families providing care rather than a focus on their differences. This search for common need is difficult when families are providing care because their support needs vary widely. It has been suggested, furthermore, that an important criterion of a caring society is flexibility, but flexibility is often viewed by planners to be antithetical to the need to structure services.

Is it possible then, to plan collective measures, requiring that need be standardized and aggregated, to effectively meet the needs of individual families? If this is a factor in the limited development of family support services, it should be looked at more closely. It might be necessary to begin to search for "similarities" of need among families even if the idea of similarity has to be stretched. This line of argument would suggest that surveys (even of a small scale) and

other types of research should be initiated, but that the unit of analysis should become the family of the handicapped and not the handicapped person. There is much to be learned by systematically asking families themselves what types of support they would find helpful. These data might then provide the categorical and aggregate data required for the planning process. Fundamental to this exercise, however, is the development of a sense of trust in families and a confidence in their ability to know what they need.

Conclusions

I began this presentation with the statement that we would like to believe that policies are developed that are in the best interests of society, handicapped individuals and their families, and human service professionals. As many of you are well aware, this is a utopian goal rather than a realistic objective. More often than not, these policies are incompatible in our present system. In maximizing the benefits to one of these three, another will be penalized. For example, we have been experiencing a considerable effort to deinstitutionalize mentally ill and mentally retarded people. The rhetoric underpinning this policy calls for providing the "least restrictive environment" for the handicapped. Two arguments are usually offered: That it is therapeutically sound and that it is less costly. The first reason emphasizes the benefits to the individual and his or her family; the second emphasizes the benefit to society as a whole. Can both be maximized? We do not really know since we have not tried it.

To some extent, the "therapeutic and less costly" criteria are the same as effectiveness and efficiency. Patients have been discharged in great numbers, resulting in cost savings to the mental health and mental retardation systems. However, these savings are misleading. The reduction of hospital places and discharges to the community have not been balanced with a comparable expansion of community support services. Community care is less costly only when community services are non-existent or inadequate. Appropriate community care might be as expensive, if not more so, than institutional care. Implicitly, our non-action places higher priority on a narrow and short-sighted definition of efficiency (cost) than on effectiveness (therapy).

Families with handicapped members need and have asked for support services. More often than not these needs, as defined by families, are for concrete services. The presence of a handicapped member creates financial stress for most families and yet our income policies offer little support unless the family has a very low income. If the cost of caring for a handicapped child is excessive, it would seem reasonable that this be recognized in our tax policies and yet, all children are treated equally, handicapped or not. If families need to make structural modifications in their homes because a handicapped child or adult lives with them, we might want to provide low-interest loans. Following the experiences of a number of European countries, we might want to develop some form of

disability allowances. For example, in 1971, the British initiated their Constant Attendance Allowance program. All families providing substantial care to a handicapped person (certified by a physician) receive a non-means-tested grant. Two arguments have been given for this decision. First, it gives families financial support to help defray the costs associated with caring for a handicapped person. Second, and probably more important, it gives families psychological support, a feeling that someone is interested in them and appreciates what they are doing.

A second type of need expressed by families is for relief in the caring function. Respite care is available in many communities, but provision is usually inadequate. In the United Kingdom, 10% of all beds in nursing homes and community-based residential care facilities (e.g., hostels) are available for respite care. Furthermore, they are protected regardless of the pressure used to free them for long-term patients. Even the mental retardation institutions are used differently. Admisssions to these institutions are on the average four times higher than in the United States. Moreover, very young children and infants, a group we will not admit, are admitted. But, in spite of higher rates of admission, especially for young children, 90% of these children remain in the institution for less than three months. In this country, 42% remain five years or longer. Why? The British use their institutions for diagnosis, short-term treatment and respite care. Institutional care is used to support families in one country, to substitute for families in another.

The list of needed services identified by families of disabled persons also includes transportation, home-making, baby-sitting, appliances, and information. They are tangible, hard services and it may be because of this that these needs cannot be maximized if the needs of the professionals are not met. For any number of reasons, professionals end up advocating for their own programs and agencies and not for families. We have a tendency to define problems in terms of solutions, and often these solutions are the provision of more resources to do those things we are already doing. Professional survival and agency expansion become the major goals. An example of this is the recently published report by the President's Commission on Mental Health. Although the report discussed prevention, family supports, and the need for innovative approaches, the major money recommendations were for expansion of the community mental health centers and training. If these funds are used to experiment with new approaches to mental illness, if they result in services to support families under stress, they might achieve the Commisssion's objectives. If they are used to continue doing what is presently being done, the major beneficiaries will be the professionals.

Policies are not likely to equally benefit society, families caring for handicapped members, and professionals. There will be trade-offs. Different criteria become critical. As advocates for the developmentally disabled and their families, we cannot make our case using

a human investment, cost-benefit, efficiency argument. Our rationale will probably be based on the notion of justice as fairness or equity. We need to argue for a reduction of existing social inequalities through a redistribution of claims and access to resources and social opportunities.

Consistent with this approach, we need to think of choice as a criterion. Twenty-five years ago, parents were encouraged to institutionalize their severely retarded children. They were told that it was better for the child and better for the rest of the family. Those who kept their children at home found few supportive services available to help them. Today, the pendulum has swung to the other extreme. Parents are told that institutional care is not in the best interest of the child or the family, and those who seek institutionalization experience considerable pressure from professionals. In neither situation are families given real choices. Choice is only viable when the available institutional care is superior care and when the community support system is of the highest possible quality. Furthermore, family care is not superior to institutional care in every case. Oftentimes, placement is desirable for the child and the family. What is important, though, are policies that allow for choice—for families to choose the best alternative.

A final comment. The issue of professional "burn-out" is being discussed more and more in the literature. We find, for example, that professionals in direct contact with the mentally retarded burn out sooner than those in management. This makes sense and leads me to ask about families providing care to handicapped persons. Who are closer than they? Can we support them before they burn out? This is our task for the future.

BARRIERS TO A FAMILY SUBSIDY PROGRAM

Harold Tapper
Association of Residences for the Retarded in Minnesota

There are two assumptions that I wish to make. First, I will follow Elizabeth Boggs in speaking primarily about families with disabled children, rather than families with disabled adult members. Second, I am not an economist and, assigned the topic of economic incentives and disincentives, I naturally assumed we were talking about money. Further, the money that I will talk about is a direct parent subsidy, and not a voucher. A parent subsidy is a payment to a parent for care provided to the parent's own child; there is no requirement in parent subsidy which states that the parent use the money to purchase services.

In my judgment, money tells us more about public policy than the rhetoric which usually surrounds that policy. While I am not an economist, I am intrigued with any analysis that has as its core the idea that money talks. There is a French phrase, "cherchez la femme." It means that, in matters of the heart, we should look for the woman. My position is that, in matters of public policy, we should look for the dollar.

I'm not the least bit uncomfortable talking about money, because it is important to all of us (we are usually in pursuit of it) and because it offers a blessedly simple way to look at the world. On the basis of money alone, the rich can be distinguished from the poor, the powerful from the weak, the upper class from the lower class. Dollars can be seen and be counted; either we have them or we don't—a behaviorist's dream! Best of all, dollars can be translated nicely into values. This is particularly true of public policy where expenditures are perhaps the best measure of the values we hold dear, and of those we spurn.

One of the problems related to this kind of analysis, however, is that the audit trail left by public dollars is sometimes hard to follow, almost like following the trail of Watergate dollars. While federal spending is not usually channeled through a Mexican bank, it does seem that public budgets are designed to conceal, rather than reveal, the true nature of public expenditures. I can recall the difficulty we experienced a few years ago as we attempted to identify the scale of federal expenditures in support of mental retardation services. More recently in Minnesota, we have attempted to do cost comparisons between state hospitals and community-based programs, only to discover that no one is quite certain how much it costs to operate the state hospitals. Some of the other presenters have introduced other confounding factors, even such as opportu-

nity costs and psychic costs, which of course make the analysis even more difficult.

The point here is that, while expenditures tell us more about public policy than does the law, bureaucratic mutterings or political speeches, the *scale* and *nature* of public expenditures are very difficult to identify. In the words of Bob Dylan, "they keep it all hid."

While public expenditures in support of the family may, in fact, be broader than I will credit here, my presentation will focus exclusively on those expenditures that can be classified as direct family subsidy, and I do this for two reasons. First, because these are the only readily identifiable expenditures in support of the family. Second, and more importantly as you will see, I will consider all other expenditures to flow from what may be an unwarranted assumption about the nature of our problem.

One fact of public policy in regards to economic incentives and disincentives for a family with a handicapped child, is clear: Public policy values and prefers care that is provided *outside* of the family setting, and *does not* value care provided by families of handicapped children. As a matter of public policy, we grossly undersubsidize family care of the handicapped person, while at the same time, we lavishly support care provided outside of that setting. Politicians may make speeches about preserving the family, but the spending policies they formulate appear to be designed to accomplish the opposite end.

In Minnesota, for example, on the day before that magic moment when a child is "placed" in a state institution, the state pays nothing for the child's care. On the day of his placement and forever after, however, the state pays about $60 every day. Now, if a visitor from outer space were to stumble upon this fact it would indeed be a strange encounter, for such a policy makes no sense at all. If money can be regarded as an incentive, and (in my judgment) it most certainly can, the state of Minnesota has created a vast disincentive for parents to maintain their children at home. Or, put another way, as a matter of public policy, the state of Minnesota values the institution far more than the family. And of course, what I've said about Minnesota applies to other states, for even where family subsidy programs are in place, they are pennies against dollars in support of institutional settings.

At this point I will define my terms. I have adopted the following definition of family care for purposes of this paper because it reflects the political reality that I've just introduced. My definition reads: "Family care is that care that is provided free of charge." From an economic perspective, there is only one factor that distinguishes the family from all other care settings, and that factor is that the family does not get paid. This definition, incidently, would rule out foster care settings, which Dr. Boggs has suggested be included in her list of family care settings, because foster parents are paid for what they do.

Now, in light of the public devaluation of the family care setting, we might set aside all further discussions of incentives and disin-

centives and ask why parents bother to care for their handicapped children at all. Of course, there are other factors at work, such as love, and loyalty, and sense of responsibility, all of which motivate the families of the handicapped child. But these are also factors that motivate care givers—in settings outside of the family, although I would guess not so strongly because they would not work without pay as parents do.

I would like to now address the following question: Why doesn't the present system for the allocation of service dollars include payment to parents as care-givers? Stated another way, what are the barriers to a parent subsidy program? In answer to this question I would say that there are five principle barriers: (1) politicians don't spend unless they have to; (2) some, if not many, people believe that paying parents is morally wrong; (3) there is a problem with accountability in parent subsidy programs; (4) parents are no match for the service establishment in the battle of public monies; and (5) *we perceive families with handicapped children as deficient or even pathologic units unable to function adequately within the accepted norms of society.*

Each barrier will now be discussed in turn. First, politicians don't spend unless they have to. It is the nature of the political process to spend only when absolutely necessary. If a law can be passed in lieu of an appropriation, a law will be passed simply because words are more politically acceptable than taxes. Therefore, in the context of our discussion, laws against child abuse, child neglect and child abandonment can be regarded as hedges against spending because they require parents to maintain their own children under penalty of law. It would appear that such laws are being strengthened, as evidenced by a new federal program designed to locate absent parents who fail to pay child support. I recall that a few years ago a national figure in our field was calling for laws absolutely prohibiting parents from terminating their responsibility for handicapped children. The point is that laws requiring parents to be responsible for their own children allow tne state to divest itself of financial responsibility for the handicapped child in the family setting, at least in so far as parent subsidy is concerned. And such laws appear to be the politician's strategy of choice.

What sometimes happens, of course, is that politicians spend without intending to do so because providers are able to exploit these programs in spite of legislative constraints. For example, the Federal Title XIX Medical Assistance Program, for all practical purposes, was a final effort by the Federal government to prop up archaic and crumbling state-operated institutions. Many of you know that Minnesota has led with efforts to pervert this program to its own ends, which is namely to provide group homes in the community. At the risk of prematurely showing our hand, it would appear that it may now be possible to certify a parent as a Medical Assistance provider for a child in his own home. The technologies are in place, only the procedural steps remain to be taken. So, the

politicians may yet provide a parent subsidy under a major federal program in spite of themselves.

A second barrier to a parent subsidy program is that some people believe that paying parents to care for their own children is morally wrong. Questions of morality about subsidizing parents are raised by those who believe that parenting is a sacred duty. The argument appears to be that love and loyalty are sacred incentives and are sufficient in themselves. (Some moralists might add fear of punishment as a standby incentive for cases in which parents are not motivated by other virtues.) From our economic perspective however, which admittedly is blessedly simple, the morality argument against subsidy can be regarded as inconsequential, since virtue has nothing to do with cash flow.

There is a third barrier to parent subsidy, i.e., the problem with accountability. Public monies are almost never allocated unless there is a mechanism to hold the payee responsible for some outcome. Laws protecting the sanctity of the family tend to restrict the data collection and quality control activities which are essential to a system of accountability. Problems related to the establishment of objectives and the evaluation of results in the family setting pose a barrier to parent subsidy. However, it would appear that the participation of parents in the case planning function, which is now mandated for individualized program planning, could be applied to the parent subsidy program. If this is the case, then the accountability question may be solvable. And, in accord with Dr. Roth's comments, a subsidy program would surely strengthen the parent's role in the joint planning process.

A fourth barrier to the parent subsidy program is that parents are no match for the service establishment in the battle for public monies. Surely one of the most important trends in our field in recent years has been the dramatic increase in the number of professional and paraprofessional persons employed by the service establishment. One of the tendencies of professional workers is to form together into organizations for the purpose of professional growth, and, of course, to lobby for public support.

Perhaps nowhere have professionals been more successful in protecting their economic turf than in education, where the law absolutely prohibits parents from educating their own children, thus insuring a professional death grip on all education dollars. Any reallocation of public dollars for parent subsidy will need to contend with the human service system, which sees public dollars as the exclusive property of the professionals. (Oddly enough, the parents and consumer advocacy groups have been as active as have been the professional organizations in support of public allocations to extrafamilial service settings. In fact, parent's organizations may have helped to create a monster which they now must battle for parent subsidy.)

The fifth and final barrier to parent subsidy is that we perceive families of handicapped persons as deficient or even pathologic units unable to function adequately within the accepted norms of

society. This final barrier to the reallocation of public dollars for parent subsidy is, to my mind, the most interesting and, perhaps, the most important of all. This perception of the families of handicapped persons as deficient or pathologic units is associated with our belief that families with handicapped children tend to have more problems in individual and marital adjustment, child-rearing practices and sibling relationships than other families, and that they are significantly affected socially and emotionally by the child's disability. In the phrase of one author writing about the families of retarded children, parents are regarded as a "pathological group with numerous intrapsychic problems."

Ten years ago, when we first began to develop group homes in Minnesota, we were puzzled by the resistance of some parents to the placement of their children in these homes. At that time, I was told that the resistance stemmed from the superficial similarity between the natural home and the group home; this similarity aroused intense feelings of guilt and inferiority among parents. If group home parents could care for their children, the parents reasoned, why couldn't they? Thus, the guilt-ridden parents actually preferred placement in a large institution.

As professionals, our response to this scenario was much tongue-clucking and head-wagging. We saw this as pathological behavior. It never occurred to us to wonder if these parents might have been able to care for their own children if they had had the benefit of a group home parent's salary, training and working conditions.

This conceptualization of the problem of a family as a deficient or pathologic unit is most important because it carries with it the explanation of why the family with a handicapped child is a problem and, more importantly, it carries with it information about what strategies will be utilized to solve the problem.

I would like to speak for a few moments on the sociology of knowledge, drawing primarily from the works of Roland Warren. The conceptualization of a social problem is what Warren, writing in 1973, called "the Diagnostic Paradigm." The related belief system, the particular way of thinking about a social problem he called the "institutionalized thought structure." Warren was studying decision organizations, which were community agencies engaged in the War on Poverty during the 1960's. In his work he discovered, as other authors had, that anti-poverty program planners tended to regard poverty as a consequence of individual deficiency. The intervention strategy associated with this paradigm (which Warren called Diagnostic Paradigm I) is that of providing services to the disadvantaged population. By this means, the deficient population will be restored, equipped, rehabilitated, and helped to become more able to cope as self-sustaining, law-abiding members of the larger society. Warren found that there were one or more services which corresponded to almost every type of deficiency in institutional participation. Further, he found that, if providing services did not lead to a solution of the problem, then the reasons for the failure

were cited as insufficient services, or poorly coordinated services. The point here is that Warren's diagnostic paradigm and attendant institutionalized thought structure defined the intervention strategy to be utilized to deal with it. I am suggesting that we have similarly defined the problem of families with handicapped children as one of inadequacy and pathology, and that we too have adopted a certain strategy to deal with it. In fact, of the 21 programs facilitating "family care" which you find in your handout, 20 are service-oriented.

This is true even though, as Warren argued, there is an alternative paradigm, one based on what he called a "dysfunctional social structure approach." The alternative paradigm, Diagnostic Paradigm II, takes as its point of orientation the aspects of the social system which produced the problem as a system output. Looked at from the standpoint of intervention strategies, Diagnostic Paradigm I indicates a need for a change in the family which is inadequate, while Diagnostic Paradigm II indicates a need for change in the social structure. Warren argued that these two approaches are mutually exclusive, cannot coexist, because in actual practice the choice of either paradigm presumes a different conceptual framework, directs attention to different variables, poses problems of a different order, and suggests different methods for solving these problems. Therefore, we have two competing diagnostic paradigms, each of which calls attention to different components of the problem, and each of which has been granted face validity. But only one of these paradigms, the approach based on the deficiency or pathology of the family unit, is part of our present institutionalized thought structure. As a consequence, we have opted for the service strategy.

What would be an alternative strategy, i.e., one associated with the Diagnostic Paradigm II, the structural change strategy? I would suggest that family subsidy is such a strategy. Interestingly enough, subsidy was also offered as a structural change strategy in dealing with poverty. But the program planners of that day, fully committed to the concept of individual deficiency, argued at first that money was not a panacea for poverty, and then, under pressure from reformers, that poverty had nothing to do with money at all! That such a patently ridiculous argument was accepted by the leaders of the War on Poverty indicates the imperviousness of the attendant belief system related to individual deficiency. I would argue that there are those today, maybe those among us, who would argue that the problems of a family with a handicapped child have nothing to do with money. And I submit that such an argument is as ridiculous today as it was 10 years ago.

The responsibility to define the problem of a family with a handicapped child falls to those of us in this room, and to the professional and advocacy organizations to which we belong. In this context, we must examine our way of thinking and knowing about the problem because our continued affinity for service strategy may constitute the most formidable barrier to a parent subsidy program. Indeed, the enemy may be us.

FAMILIES OF THE DEVELOPMENTALLY DISABLED: IMPLICATIONS FOR RESEARCH AND THE PLANNING AND PROVISION OF SERVICES

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In recent years, interest in the problems experienced by persons afflicted with such developmental disabilities as mental retardation, epilepsy, cerebral palsy and autism has increased. Such interest may be attributed to several interrelated factors: medical technology which has extended the lives of many persons so afflicted; policies of deinstitutionalization which have increased their visibility in the community; legislation mandating the provision of education and other services to the developmentally disabled and others in the community; the advocacy of organized groups on their behalf, such as the National Association for Retarded Citizens and its local affiliates, United Cerebral Palsy Associates, the Epilepsy Foundation of America, and the National Society for Autistic Children; as well as increased knowledge about developmental disabilities, their causes and treatment strategies appropriate to each.

Treatment of developmental disability includes anticipatory intervention to prevent the occurrence of disabilities or treatment of such occurrences before they evolve into life-long problems for those afflicted and their families. We know that actions can be taken to prevent many of the problems associated with developmental disabilities through measures of environmental protection, proper prenatal, maternal and infant care, adequate diet, genetic counseling, prenatal screening programs; and treatment of birth defects in newborn babies. Such knowledge creates a feeling of urgency that such actions in fact *be* taken.

Current Projects for the Developmentally Disabled and Their Families

Despite the possibility of future intervention to prevent or treat developmental disabilities, thousands of people have already been born with and live with a developmental disability that either could not have been or was not prevented. A nationwide search by the conference leadership uncovered information about a few projects undertaken by a few states to help families deal with some of the problems that attend the care of a developmentally disabled member (Appendix A). Each project is unique in some respect.

Oklahoma, Montana, Rhode Island, Massachusetts, and Minnesota have developed subsidy programs to offset some of the extraordinary expenses encountered by families caring for develop-

mentally disabled members. In Oklahoma and Montana, such subsidies are targeted at adoptive families of hard-to-place children, some of whom are undoubtedly developmentally disabled. In Rhode Island, such subsidies are targeted not only at adoptive families but also at foster and natural families of formerly institutionalized retarded members, both children and adults. Massachusetts' subsidy program also is for families with retarded members, both children and adults, but apparently is restricted to covering costs related primarily to special training and psychological counseling of parents and physical therapy for afflicted members. Minnesota's subsidy program is only for families with retarded children, not adults, but covers a broader range of service and other costs than Massachusetts' program, such as physical therapy, special equipment, transportation, medication, babysitting, respite care, special clothing, special diet, and medical and dental care not covered by insurance, public assistance or social service monies (Minnesota Department of Public Welfare, 1977).

Other states, such as Virginia, Pennsylvania, and Nebraska have focused attention, not so much on the provision of financial subsidies, but on the development of community resources to facilitate family care of retarded members. In Pennsylvania, such resources include respite care, homemaker services, transportation, baby-sitting, therapy, and special services that have been termed "innovative." In Virginia, resource development pertains specifically to the training of families of formerly institutionalized mentally retarded members while, in Nebraska, resource development has been characterized as "broad," involving a multi-dimension pilot parent program. Other projects in Washington, Oregon, California and other states include respite care, infant development and childhood intervention programs of various types.

In reviewing these thumbnail project sketches, some general observations may be made:

1) there is no indication of how these projects are integrated with or into the larger social welfare system, i.e., health, education, income maintenance, the personal social services, housing, or employment and manpower;
2) all of the projects place emphasis on *families* of the developmentally disabled;
3) the projects are focused primarily on the mentally retarded as opposed to persons having other kinds of developmentally disabilities;
4) they tend to be weighted toward children;
5) none appear to attempt to combine the provision of financial help with the development of a range of community resources;
6) few seem to attend to the special psychological problems of families of the developmentally disabled;
7) none are anticipatory or designed to deal with the prevention of the occurrence of developmental disabilities; and

8) the fact that all of the projects could be reviewed within a relatively brief paragraph is suggestive of the very early stage of development in which planning for the developmentally disabled is taking place.

A discussion of these observations may be in order as they relate to families of the developmentally disabled since, as noted, each of the projects is addressed to such families. Also, increasingly, the family is coming to be recognized as a key resource, not only for the developmentally disabled, but for all individuals and society as well. Therefore, critical to thinking about the developmentally disabled is some conceptual understanding of the family which not only raises questions for needed research, but suggests directions for the planning and provision of services supportive of family care.

Clues for Research

One approach to viewing the family in relation to the developmentally disabled is to perceive the family as a social system that progresses through defined sequential stages (Hill, 1971; Zimmerman, 1976) in a rapidly changing environment that has been characterized in other contexts as turbulent (Terreberry, 1971). Such a perspective takes into account certain systematic characteristics of the family that raise questions for research and have implications for service planning and provision for families of the developmentally disabled.

One such characteristic pertains to the functions the family performs for its members and society at large. From this vantage point, the family is perceived as a goal oriented task-performing system performing such functions as: 1) the physical maintenance and care of family members; 2) the addition of new members through procreation and their relinquishment when they mature; 3) the socialization of children for adult roles; 4) the maintenance of social control, both within the family and between the family and outside groups; 5) the maintenance of family morale to facilitate task performance of family members; and 6) the production and distribution of goods and services necessary to family members. These tasks and functions vary over the life cycle of the family. When they are specific to stages and phases of the family life cycle, such as the establishment stage, the childbearing stage, the school stage, the adolescent stage, the launching stage, the post-parental stage, and the aging stage, they form the basis for family developmental tasks (Hill, 1971).

The questions that may be asked in relation to the developmentally disabled and their families are: In what ways does a developmentally disabled member affect a family's capacity to carry out its various and separate functions as a task performing system? How do these effects change over the life cycle of families of the developmentally disabled? Which family functions are the most seriously affected? What services need to be developed to enable such families to continue to perform their tasks, and how should such services be adapted over the life span of these families? What are

the differential effects of the different developmental disabilities on the capacity of families to perform their various functions?

Another systemic characteristic of the family with implications for research regarding families with developmentally disabled members is the interrelatedness of family positions or the interdependence of component parts that comprise the family structure. Each position in the structure encompasses certain functions that must be performed if the family as a system is to perform its functions for its members and society. A network of family relationships based on shared values and expectations develops through the interactions of people in these positions, such as husband-wife, father-daughter, father-son, mother-daughter, mother-son, sister-brother, and so forth.

This network of family relationships, which varies with class and culture, tends to persist over time until it is disrupted by the behaviors of one of the occupants in one of the family positions. Divorce, separation, or death, particularly of those in leadership positions of husband-father and wife-mother, results in a deficit in family structure. Tasks that had been performed by occupants in these positions must be reallocated to other remaining family positions. These positions tend to become overburdened with having too many tasks to perform. On the other hand, too many occupants for limited family positions results in an excess of family structure, that is, in overmanned rather than undermanned family positions (Hill, 1971).

In the case of families of the developmentally disabled, questions that might be asked include: What is the nature of the interactions in families of the developmentally disabled? What are the effects of a developmentally disabled member on these interactions? What are the effects of each of the components of socioeconomic status—income, occupation and education—and racial and ethnic background on family interactions relating to the developmentally disabled? What are the effects of family size or the number of filled and unfilled family positions on family interactions in families of the developmentally disabled? In the case of divorce, separation, or death, particularly of a mother or father, how are tasks associated with such positions reallocated? To whom are they assigned? How does the reallocative process differ from that which occurs in other families? What are the consequences of this process for developmentally disabled family members? What are the effects of socio-economic status and racial and ethnic background on the reallocative process and its outcomes for such members? What might such consequences suggest for the planning and provision of social and other services for the developmentally disabled? What is the nature of interactions in blended or reconstituted families with developmentally disabled members? In situations of overmanned family positions, to whom and by whom are particular tasks assigned? Again, what are the consequences of such task assignments for the developmentally disabled member?

Another systemic characteristic of the family, its boundary-maintaining nature, raises still more interesting questions for research on developmentally disabled persons and their families. This characteristic suggests that the family is to some extent closed and autonomous (Hill, 1971). The boundary of any system may be conceived as the demarcation line separating the system from its environment, which may be discerned by patterns of interaction that differ in degree and kind within the system and between the system and its environment (Katz & Kahn, 1966). As a semi-closed, boundary-maintaining system, the family is perceived as opening selectively to engage in transactions with other social systems, such as schools, churches, social agencies, hospitals, and work places, through liaison roles built into family positions (Hill, 1971).

Among questions that might be raised by this systemic characteristic in relation to the developmentally disabled are: What are the effects of the family's semi-closed nature on the willingness of families to seek help from external systems in caring for developmentally disabled members? As a corollary, what are the effects of the family's semiclosed nature on the services and programs of external systems serving the developmentally disabled? What is the nature of the interactions between family members performing liaison roles and those performing similar roles for other systems? What are the effects of socioeconomic status and racial and ethnic background on such interactions? How can families be helped to perform their liaison role more effectively with the developmentally disabled and other social systems? How can those performing liaison roles for other social systems, such as information and referral/service specialists, be helped to better perform their functions relative to families of the developmentally disabled? What is the nature of their interactions with service components within their system and other relevant systems? Do they perform a feedback function about the needs of developmentally disabled persons and their families? Do they systematically gather data that is relevant to planning for such persons and their families? If so, do they make such information available to advocacy groups, planners, and policy makers to create a political environment favorable to the development of needed resources?

Another systemic characteristic of the family, its equilibrium-seeking and adaptive nature, raises still other questions for research regarding families with developmentally disabled members. The notion of equilibrium as it pertains to the family suggests that there is a range of possible states within which the family can function. The family can survive as a system as long as demands relative to its interaction patterns do not exceed this range. When one or more family members become estranged and leave the system, disrupting established interaction patterns, the point at which this range has been exceeded is readily apparent. Because of its variable size and changing age composition, the family probably is more vulnerable to internally-induced change and equilibrium upset than other social systems (Hill, 1971). Such vulnerability proba-

bly pertains to families with developmentally disabled members more than other families. Further, in the case of families with developmentally disabled members, the ratio of demands to interaction patterns may well go beyond the range within which such families can effectively function, creating a state of potential family disequilibrium or crisis.

Crises are produced by hardships imposed on the family system. Hardships may be defined as complications in a crisis-precipitating or stressful event which require competencies from the family that the event itself may have temporarily paralyzed or made unavailable. Stressful events become crises in keeping with the definitions that families accord to them and the resources they have for dealing with them (Hill, 1958). Thus, it is important to ask: What specific hardships does the care of a developmentally disabled member place on his or her family? How are such hardships perceived by the family? What psychological, social, and financial resources do such families have for dealing with these hardships? What resources can external systems bring to bear on a crisis situation to facilitate a state of greater equilibrium in these families? What strategies are most appropriate for different provisions and for what types of families? To what extent and in what ways do external systems contribute to family disequilibrium?

States of equilibrium and adaptation are made possible through processes of negative and positive feedback. While negative feedback triggers behaviors that are more congruent with basic system values, positive feedback triggers behaviors that are more discrepant with basic system values. Positive feedback is considered essential to the morphogenic process through which the family changes its structure and performance in relation to changing needs of family members as well as to changing requirements of the environment (Hill, 1971). Thus, among the questions that might be asked in relation to the morphogenic process and families of the developmentally disabled are: What have been the effects of changing environmental requirements regarding deinstitutionalization on the morphogenic process in such families? In what types of families is the morphogenic process most likely, or conversely, most unlikely to occur? How can the morphogenic process be encouraged in families of the developmentally disabled? What are the effects of such variables as family stage of development, family structure, racial and ethnic background, and socio-economic status on the morphogenic process within these families?

Implications for Service Planning and Provision

The planning of services for the developmentally disabled and their families requires answers to the questions that have been presented if such services are to be effective. Following Kahn (1969), planning is defined as "policy choice and programming in the light of facts, projections, and the application of values." Therefore, relevant known information should be incorporated into the planning process and relevant information not known should be obtained.

Perceiving the family as a social system that develops through sequential stages in a rapidly changing environment provides a framework within which planning for the developmentally disabled and their families might begin. Such a perspective, in highlighting the importance of family functions and the mechanisms through which and by which these functions are performed, helps to clarify the overall tasks of social services which Kahn and others have stated are to facilitate role performance and family functioning (Kahn, 1973; Zimmerman, in press). Consistent with such tasks in relation to families of the developmentally disabled could be the provision of such services as baby-sitting, companion-sitting, transportation, respite care for emergencies and vacations, housing adaptations, homemaker services, special subsidies, and other specialized services and provisions.

The family developmental/systems perspective, in highlighting the importance of family structure for the performance of family functions, suggests the need for services that buttress family structure through socialization and developmental provisions for family members; through provisions for access, information, and advice; and through provisions for therapy, help, and rehabilitation when needed. In relation to families of the developmentally disabled, many of the specific services listed above as well as many others could apply. Further, the family developmental/systems perspective, in highlighting the semi-closed nature of the family and the importance of its liaison roles vis-a-vis external systems, suggest that need for access provisions such as information and referral services, advocacy, and legal services. It also suggests the need for liaison training for persons performing liaison roles for the family and for the systems within which the family interacts with its developmentally disabled members.

In addition, such a perspective, in highlighting threats to family equilibrium and adaptation from both internal and external sources, including the long-term continuing care of a developmentally disabled member, suggests the need for the planning and provision of services in *all* areas--health, education, income maintenance, employment and manpower, housing, and the personal social services—adapted to the particular needs of the developmentally disabled and their families. It further suggests that the morphogenic process in families of the developmentally disabled would be more easily assured through such preventive measures as adequate pre-natal, maternal and infant care; proper nutrition; genetic counseling; safety precautions, and environmental protection.

Finally, in highlighting the sequential stages of family life, the family developmental/systems perspective points to the need to plan for the provision of different kinds of services for different stages of family development. For example, genetic counseling and pre-natal, maternal and infant care services would be appropriate at family formation and child-bearing stages of family development; at preschool and school-age stages, parental training in child man-

agement would be appropriate; and at later stages, parental counseling about alternative living arrangements for a developmentally disabled member may be appropriate.

Concluding Notes

Just as positive feedback can enable the family system to adapt and grow, information and feedback to the service system about developmental disabilities, their causes and effects, can enable the service system to become more adaptive and responsive to the needs of the developmentally disabled and their families. Indeed, environmental demands require agencies to adapt their programs to meet the needs of the developmentally disabled, as evidenced by legislative mandates for community-based treatment programs and the mainstreaming of handicapped children in education. Increasingly, therefore, community agencies will be required to attend to the needs of developmentally disabled persons and their families.

According to a report of the Family Task Force of the MR-MH Advisory Council of the Minnesota Department of Public Welfare (1978), community response to the needs of the developmentally disabled has been slow. An examination of federal, state, and local programs by the Task Force indicated that few financial and social supports are available to families to enable them to care for disabled members at home (particularly middle-income families whose access to many public goods and services is precluded because of income eligibility criteria) despite an array of services and programs that seem to be more generally available, at least in urban communities. Critical service gaps and deficiencies identified by the Task Force in relation to developmentally disabled persons led it to recommend a comprehensive program for handicapped children. Its advocacy for such an approach, however, is contradicted by its exclusion of adults, as well as by its biased attention to retarded persons. While a comprehensive approach to any problem is to be desired, the development of a presumably all-inclusive program for each specialized population carries the risk of continuing the present fragmentation of services about which so many complain. Further, in taking such a position, the Task Force negates larger, more comprehensive developments in the social services that are taking place throughout the country, of which programs for the developmentally disabled could and should be a part.

The message thus becomes clear for all who are interested in the planning and provision of services to meet existing and emerging human needs—for *all* populations, not the developmentally disabled alone. As efforts continue to shape and develop our social service system into an identifiable system (Kamerman & Kahn, 1976) which will provide a range of human services on an increasingly universal basis, specialized provisions for special populations such as the developmentally disabled and others must be developed and integrated into it. Only then will the system be comprehensive and accessible to all and reflective of a truly caring society. Only then will family care be realistically feasible for many of the developmentally disabled.

CONFERENCE REVIEW

Gordon C. Krantz

In reviewing the seven presentations that make up the bulk of the conference proceedings, one is struck by the essential unity of outlook that the presenters reveal.

The greatest underlying unity among the presentations is the deep concern for the interests of the developmentally disabled person and his family. This concern is not maudlin; it is consciously tempered with the limitations of reality and is a wholehearted and non-paternalistic concern. The individual is viewed as worthy in some ipso facto sense, and the family members are valued as people. There is genuine recognition of the situation with which the parents (and the developmentally disabled family member) must deal on a daily basis. In their outlooks, all of the presenters reveal many years of direct contact with the situations that they describe, and these outlooks reveal their participation and understanding.

A second unity in the presentations is the recognition that, even in the psychic and social factors of family care, the common denominator in our culture is the equation of values with concrete resource allocation in the form of conventional economics. This trend built like a cresting wave throughout the conference. It began with the Opportunity component of Horejsi's M-C-O Framework. Farber tempered this with his caution that society does not yet have a cure to every ill. Psychic resources were combined by Roth into an equation that included family income and expenses. Boggs presented an explicit matrix of goods (including personal and social "good" things) and dollar costs. Factoral dollar allocations, as percentages of the Gross National Product, were reviewed by Moroney. Finally, at the crest of the wave, Tapper pointed out that society casts its vote for extra-familial values with its dollars. With Zimmerman's systematic view of family futures, the swell of the wave carried forward a perspective that locates ultimate solutions in specialized provision of a fully developed range of human services for developmentally disabled persons.

Models for Family Care

The conference participants presented a series of models designed to enable a constructive view of family care for developmentally disabled members. These models, variously expressed, represent alternative ways of taking a cross-section of the situation so as to know what should be done to bring about desired results.

Horejsi's M-C-O model $\left(FC = \frac{M \times C \times O}{P}\right)$ shows where leverage

can be exerted so as to enhance the ability of the family to provide care to its developmentally disabled children. Like most explanatory models, it does not provide answers but allows a mode of thinking that can be used to discover answers; if means are sought to increase the "O" term (Opportunity), then family ability to provide care ("FC") may be increased.

Roth's model describes the utility of a developmentally disabled child to the family. It is an economist's model in which utility carries with it the human values that are involved. His formula states that family utility equals (is a function of) an equation in which some function or family income, current psychic satisfaction, and anticipated future psychic satisfaction are balanced against current expenses and anticipated future financial and psychic expenses. In equational form, the Roth model appears to be:

Family Utility = (Family Income) (Current Psychic Satisfaction) (Anticipated Future Psychic Satisfaction) (Current Expenses) (Anticipated Future Expenses)

The Roth model clarifies the role of hope in the situation through its anticipation of the future.

The matrix presented by Boggs in Figure 1 is an analysis of resource allocation. The elements in the matrix allow an accounting of sources and objects of the economics involved in family care of developmentally disabled members.

The model presented by Tapper is a starkly simple one: The values and strategies of society can be determined by examining where it puts its money. This is a political model and as such it takes into account the likelihood that values will influence allocation and that allocations can be moved so as to create or at least reinforce values. For example, resources seem now to be allocated in accordance with the values of extra-familial care, and efforts to secure greater allocation of resources to support the family can at least reinforce the attribution of value to the family.

The final model, presented by Zimmerman, views the family as a system with a goal-orientation, a network of relationships among its elements, a boundary that it maintains, and the capacity for maintaining equilibrium and acting in an adaptive manner. A model of this type enables an approach to be made to family care in such a way that the interrelationships of cause and effect can be anticipated.

None of the models excludes the others. Each is one of the several ways of looking at the situation of family care for developmentally disabled members. Each model is fitted for a somewhat different set of approaches, but nothing would prevent the simultaneous application of all of the models, each by those who find it to be the most compatible with their interests, goals, and styles of operating.

Conflicts Within Family Care

The seven presentations revealed some of the contrasts, the tensions and the conflicts that are inherent to the field of family care for

developmentally disabled members. In some instances, the points of view that were presented were polar and superficially may appear to be contradictory. Some of the presentations stressed the family and others stressed society as the locus of causes, values, responsibilities or capability for improving the situation of developmentally disabled people. It is difficult to assert the one without appearing to deny the other. As a whole, however, the presenters gave attention to all major aspects of the interaction between the family and society.

Overall, some of the conference was abstract and formulary and other portions were concrete and individual. The abstract approach allows an analysis of the situation which is not possible on the basis of only considering particular instances or even immediate reality. A formulary or model-based approach allows thought to be taken as to where one might find the pressure points and leverages that would enable humane action. The concrete approach has the virtue of calling one back to the actual life situations that one hopes to impact. The concrete and the human were typified by Tapper's reference to love, loyalty, and a sense of responsibility.

Another more full set of outlooks ranges from the assumption of rational behavior on the part of both family and society to the evidence that at least some irrationality is to be expected in each. Current social policies show some distrust of the rationality of the family in the controls that they place around the various supports to family function and in the vesting of decision power in third parties when support is given to individuals and families. The expectation of rationality and irrationality is somewhat paralleled in social action programs by dependence upon family responsibility versus dependence upon social and regulatory control. To the extent that this conference took a position on this continuum, the presenters appeared to have a somewhat stronger than neutral assumption of rational self-interest in decision-making on the part of consumers.

The tension between what society finds to be generally convenient, beneficial, and feasible on the one hand, and the value of the family as a human institution on the other, was also evident in the formal presentations. Again, the modal positions of the participants seemed to be in the direction that favors the family values. At the same time, there was repeated recognition of the fact that the nuclear family is no longer the only option in society, and it is no longer the only valued kind of family.

As with the alternative models, these contrasts or tensions in the field represent different ways in which to approach the subject of family care for developmentally disabled members. The choices of specific positions among them may well be determined by the perceived needs that are specific to the advocate in a particular situation and at a particular time.

Unities of Outlook in Family Care

Overall, the conference presentations reveal certain commonalities of outlook among the participants. These commonalities were

also reflected in the unrecorded discussion that followed each presentation. The unity of the seven presentations has already been discussed in relation to a concern for the interests of the developmentally disabled individual and the family. The view of the family, however conceived by the presenter, was one of value and worth. Some of the value was presented as intrinsic to the family as a social institution; some of the value was attributed to the effects that the family creates for the developmentally disabled person and also for society in general.

Another commonality was the value placed upon participation in decision-making by the developmentally disabled person and by other family members. This attribution of value was sometimes related by the presenters to the current emphasis upon participation in social action programs. In making this reference, several of the presenters recognized the additional burden that participation places upon the consumer and the consumer family. It must be recognized, concluded the presenters, that there is a trade-off between the benefits and the costs of participation. On balance, the common conclusion seemed to be that, while the burden must be recognized, the benefits outweigh the burden.

As to the future, the closing presentation raised the many questions that must be borne in mind when society intervenes on behalf of family care. After reviewing the identified research and development projects (See Appendix B), Zimmerman pointed out the essential interrelationship between family care of developmentally disabled members and the overall human service system that is operated by society.

FAMILY CARE AND PUBLIC POLICIES

Gordon C. Krantz

In addition to the prepared and formal presentations that are reproduced in these conference proceedings, the final afternoon of the conference was devoted to a structured analysis of relevant public policy options that might be advanced to improve family care to developmentally disabled members. This concluding session of the conference was designed as a summary and integration of the sessions for all those who attended.

The relation of public policy analysis to the study materials and the formal presentations is shown in Figure 3.

All those who were at the conference were assigned to discussion groups. In each of the five groups were consumers and parents, professional workers, a representative of an exemplary service programs designed to facilitate family care, one of the workshop's presenters, and a skilled group facilitator.

Worksheets were provided to each group in order to channel the discussion. The first worksheet called for the identification of one issue or public policy option that would engage the group's attention for resolution. This was intended to focus the group discussion upon something that could be brought to a conclusion in the three hours available.

The second worksheet requested the group to briefly state the problem or the issue to be addressed, to give an example or illustration, to state the goal to be reached through the policy, and to make a clear statement of the policy that would be required in order to reach the goal. The policy statement was to specify who should adopt the policy and who or what should be influenced by it. Possible unwanted consequences or side effects were to be noted if they were anticipated and provision was made for explanatory comments.

In the time allocated to discussion, only skeletal coverage of these points was possible and not all of the points could be made fully explicit. The focus of the task was upon the promulgation of a policy statement.

The definition given in the working materials was:

"A public policy option is:

something that could be done

as a matter of national policy

by way of position statement, set of principles, law, regulations, pattern of appropriation, or similar action

on the part of any branch of government or a national public or private group

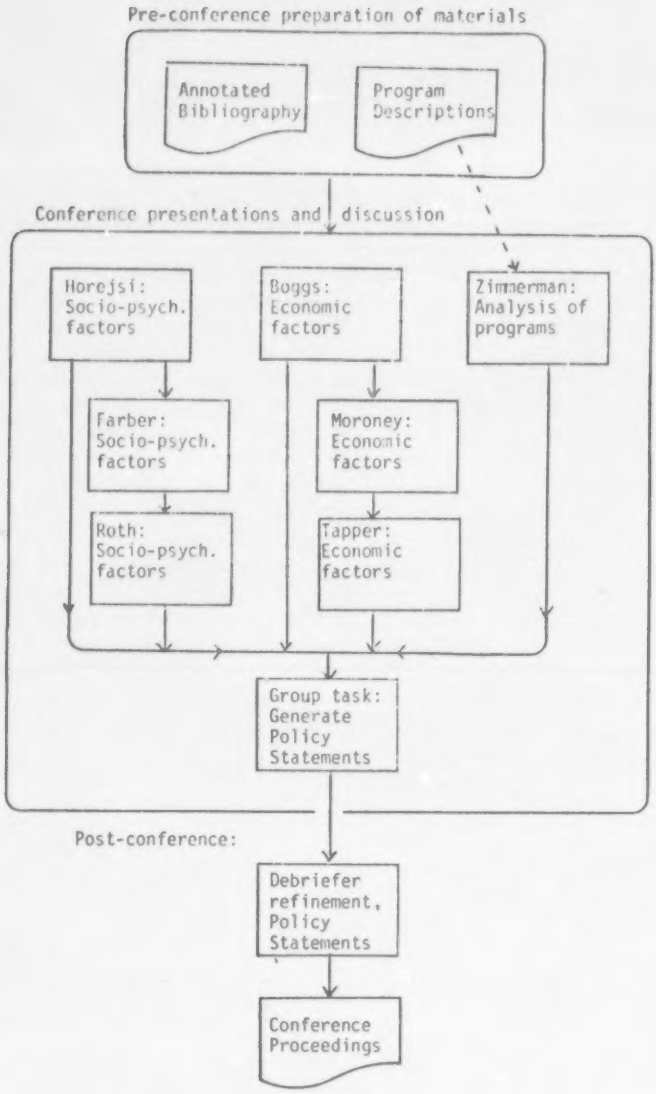

Figure 3

Derivation of Policy Statements from pre-conference documents and from conference presentations and discussion.

so as to bring about

more, more effective, better quality, easier, or more rewarding (to all parties) life as a family member

by developmentally disabled persons."

Before adjourning, each group wrote out its proposed policy statement together with some supportive rationale. Each group also designated one or more "debriefers," people who could respond to telephone follow-up, so as to clarify the policy statement and backgrounds. The designation of debriefers was intended to compensate for the fact that not all of the discussion could be recorded.

The debriefers were contacted approximately two weeks after the conference and were asked to analyze the policy statements and to expand them phrase by phrase. The statements were then reworded on the basis of this analysis, so as to reflect as accurately as possible the thinking of the discussion groups.

The resulting proposals for public policy show the nature of the concerns expressed by workshop participants. No order of priority was assigned among the statements, which are listed here in random order.

- Parent organizations should urge federal, state, and local Developmental Disability agencies to adopt a policy of funding local respite services.
- (It should be public policy that) in formulating, planning, implementing and/or funding services, the developmentally disabled person and/or his family has the right to participate in any decision-making process. Outreach efforts by power holders should be directed toward allowing (providing means for) the family or individual to choose among and influence choices of alternatives for services.
- It should be the policy of public and private service agencies and organizations to provide parents of developmentally disabled persons, and the disabled individuals themselves, with information about the benefits and services provided by consumer organizations.
- It should be public policy that support be given to parent-directed training and counseling services that have the goal of family integrity. In pursuit of this goal, the services should permit the maximum development of all members and provide for the greatest possible self-determination.
- It should be public policy that the level of government which provides funds for service programs should coordinate the determination of the services needed, and should include consumers/parents and provider agencies in this process. Public policy should embody a philosophy that recognized the rights of developmentally disabled individuals and their families, including:

  1) equal participation in the design of the individual's service delivery system;

2) support services to maintain the home environment if that is the plan or choice;
3) availability of a range of alternative living arrangements to meet individual needs; and
4) an effective and individually appropriate educational process.

- It should be federal policy, to be implemented through reform of tax laws and categorical aid programs, to encourage the development of an accountable and flexible system of cash assistances and services—both one-time (i.e., costly equipment and removal of architectural barriers in the home) and outgoing—needed by people who are developmentally disabled.

The concerns that are evident in the formal presentations are also apparent in these policy proposals. Many of the proposals were given initial formulation during the discussion periods that followed the formal presentations of the conference.

The policy statements that are listed above are recognized as preliminary and not fully comprehensive. They would warrant a second consideration under less limited time constraints in order to work out their implications for specific action and to select the policies that most urgently need implementation. However, they do represent the consensus of a group of concerned and well-informed people who devoted two days to thought, discussion and the formulation of these options.

The presentations and discussion throughout the conference highlighted the important and often unmet needs of families with developmentally disabled members. Although the concept of family care has many facets and many forms, there was consensus around the need to improve these approaches to service on behalf of developmentally disabled persons. It is hoped that the results of this conference will increase the attention of policy-makers on the potential for models of family care.

REFERENCES

These references are cited by the conference speakers in their texts. They have been compiled into a single list to avoid duplication. See also the Annotated Bibliography, printed as a separate section of this publication.

Aanes, D., & Whitlock, A. A parental relief program for the MR. *Mental Retardation*, 1975, **13** (3), 36-38.

Barsch, R. H. *The parent of the handicapped child: The study of child-rearing practices*. Springfield: Charles C. Thomas, 1968.

Bayley, M. *Mental handicap and community care: A study of mentally handicapped people in Sheffield*. Boston: Routledge & Kegan Paul, 1973.

Beck, D. F. *Marriage and the family under challenge: An outline of issues, trends and alternatives*. New York: Family Service Association of America, 1976.

Bergsma, D., & Pulver, A. E. *Developmental disabilities: Psychological and social implications*. New York: Alan R. Liss, Inc., 1976.

Birenbaum, A. On managing courtesy stigma. *Journal of Health and Social Behavior*, 1970, **11**, 196-206.

Birnbaum, H. *The cost of catastrophic illness*. Lexington, MA: D. C. Heath & Company, 1978.

Bruininks, R. H., Morreau, L. E., & Williams, S. M. *Issues and problems of deinstitutionalization in HEW Region V* (Project Report No. 2). Minneapolis, MN: University of Minnesota, Information and Technical Assistance Project on Deinstitutionalization, 1979.

Butler, E., Bjaanes, A., & Hofacre, S. Referral and utilization of services and agencies by community care facilities. Paper presented at the Annual Meeting of the American Association on Mental Deficiency, Portland, OR, May 1975.

Caplan, G., & Killiea, M. (Eds.). *Support systems and mutual help: Multidisciplinary explorations*. New York: Grune & Stratton, 1976.

Cohen, D. K., & Farrar, E. Power to the parents? The story of education vouchers. *The Public Interest*, Summer 1977, 72-97.

Cohen, J., Butter, I., Deline, S., & Nutter, R. *Benefit-cost analysis for mental retardation programs: Theoretical considerations and a model for applications*. Ann Arbor: Institute for the Study of Mental Retardation and Related Disabilities, 1972.

Collins, A. H., & Panacoast, D. L. *Natural helping networks: A strategy for prevention*. Washington, DC: National Association of Social Workers, 1976.

Community-based systems of temporary family supports and integrated respite service systems: A resource bibliography. Omaha, NE: The Center for the Development of Community Alternative Service Systems (CASS), 1978.

Culley, J. D., Van Name, J. B., & Settles, B. H. Measuring the indirect cost of child care. *Public Welfare*, Fall 1976, 6-12.

Culver, M. Intergenerational social mobility among families with a severely mentally retarded child. Unpublished PhD dissertation, University of Illinois, Urbana, 1967.

Cunningham, J. J. Institutionalization of post-school aged retarded persons of mild and borderline intelligence. Unpublished EdD dissertation, University of Illinois, Urbana, 1975.

Doernberg, N. L. Some negative effects on family integration of health and educational services for young handicapped children. *Rehabilitation Literature*, 1978, **39**, 107-110.

Doyle, C. A. Letter to Senator Robert Dole. *Congressional Record*, 1978, **124**, 12.

Dunlap, W. R., & Hollingsworth J. S. How does a handicapped child affect the family? Implications for practitioners. *The Family Coordinator*, July 1977, 286-293.

Dupont, A. Severely mentally retarded children living at home: A symposium. *International Journal on Research Exchange and Practice in Mental Retardation*, 1975, **1**(3), 107-145.

Edgerton, R. B. *The cloak of competence*. Berkeley: University of California Press, 1967.

Ehlers, W. H., Krishef, C. H., & Protharo, J. C. *An introduction to mental retardation*. Columbus, OH: Charles E. Merrill, 1973.

Fanshel, D., & Shinn, E. G. *Dollars and sense in the foster care of children: A look at cost factors*. New York: Child Welfare League of America, Inc., 1972.

Farber, B. Effects of a severely mentally retarded child on family integration. *Monographs of the Society for Research in Child Development*, 1959, **24**, No. 2.

Farber, B. Perceptions of crisis and related variables in the impact of a retarded child on the mother. *Journal of Health and Social Behavior*, 1960, **1**, 108-118.

Farber, B. *Mental retardation: Its social context and social consequences*. Boston: Houghton Mifflin, 1968.

Farber, B. Parental decision-making: Justifying transgressions. In C. A. Swinyard (Ed.), *Decision-making and the defective newborn*. Springfield: Charles C. Thomas, 1978, 123-157.

Farber, B., & Jenne, W. C. Interaction with retarded siblings and life goals of children. *Journal of Marriage and the Family*, 1963, **25**, 96-98.

Farber, B., Jenne, W. C., & Tiege, R. Family crisis and the decision to institutionalize the retarded child. *Council for Exceptional Children Monograph Series*. Series A, Number 1, 1960.

Frolich, P. *The 1967 national survey of institutionalized adults: Residents of long term medical care institutions*. Washington, DC: US Department of Health, Education and Welfare, DHEW Publications No. (SSA) 75-11803, 1975.

Gearheart, B. R., & Litton, F. W. *The trainable retarded: A foundations approach*. St. Louis, MO: C. V. Mosby, 1975.

General Accounting Office. *Returning the mentally retarded to the community: The government needs to do more*. Washington, DC: General Accounting Office, 1977.

Goode, W. J. *The family*. Englewood Cliffs, NJ: Prentice-Hall, 1964.

Graham, J. R., Friedman, I., Lilly, R. S., Thiesen, J. W., & Hinko, E. N. The home environment perception scales. *Journal of Community Psychology*, 1975, **3**(1), 40.

Grossman, F. K. *Brothers and sisters of retarded children: An exploratory study*. Syracuse: Syracuse University Press, 1972.

Hall, W., & Young, C. (Eds.). *Proceedings — genetic disorders: Social service interventions*. Pittsburgh: University of Pittsburgh Graduate School of Public Health and Public Health Social Work Program, March 1977.

Heal, L. W., Sigelman, C. K., & Switzky, H. N. Community residential alternatives for the mentally retarded. In N. R. Ellis (Ed.), *International review of research in mental retardation*. New York: Academic Press, in press.

Hobbs, N. *The futures of children*. San Francisco: Jossey-Bass, 1974.

Holroyd, J., Brown, N., Wikler, L., & Simons, J. Q. Stress in families of institutionalized and noninstitutionalized autistic children. *Journal of Community Psychology*, 1975, **3**(1), 26.

Horejsi, C. R. *Deinstitutionalization and the development of community based services for the mentally retarded: An overview of concepts and issues*. Missoula, MT: University of Montana, Project on Community Resources and Deinstitutionalization (Grant No. 90-C-341), Office of Child Development, US Dept. of Health, Education, and Welfare, August 1975.

Intagliata, J. C. The use of family care homes as a community placement for mentally retarded persons in New York State. Paper presented at the annual convention of the American Association on Mental Deficiency, May 19, 1978.

Intagliata, J. C., Willer, B. S., & Cooley, F. B. Cost comparison of institutional and community-based alternatives for mentally retarded persons. MS submitted for publication, SUNY Buffalo, 1978.

International League of Societies for the Mentally Handicapped. *Stress on families of the mentally handicapped*. Paris, March 1966.

Jacobs, J. *The search for help: A study of the retarded child in the community*. New York: Brunner-Mazel, 1969.

Jaffee, B., & Kline, D. *New payment patterns and the foster parent role*. New York: Child Welfare League of America, 1970.

Jaslow, R. I., & Spagna, M. B. Gaps in a comprehensive system of services for the mentally retarded. *Mental Retardation*, 1977, **15**(2), 6-9.

Jones, K. *Opening the door: A study of new policies for the mentally handicapped*. Boston: Routledge & Kegan Paul, 1975.

Jones, P. P., & Jones, K. J. the measurement of community placement success and its associated costs. MA thesis, Brandeis University, The Heller School, Waltham, 1976.

Justice, R. S., Bradley, J., & O Connor, G. Foster family care for the retarded: Management concerns of the caretaker. *Mental Retardation*, 1971, **9**(4), 12-15.

Kahn, R. Job burnout: Prevention and remedies. *Public Welfare*, Spring 1978, 61-63.

Kakalik, J. S., Brewer, G. D., Dougharty, L. A., Fleischauer, P. D., Genesky, S. M., & Wallen, L. M. *Improving services to the handicapped child with emphasis on hearing and vision impairments*. Santa Monica: The Rand Corporation (R 1420 HEW), May 1974.

Katz, E. *The retarded adult in the community*. Springfield: Charles C. Thomas, 1968.

Keniston, K. How public policy affects the family: Increasing parent power. *Public Welfare*, Spring 1978, 12-17.

Keniston, K., & The Carnegie Council on Children. *All our children: The American family under pressure*. New York: Harcourt, Brace, Jovanovich, 1977.

Krantz, G., Bruininks, R., & Clumpner, J. *Mentally retarded people in state-operated residential facilities: year ending June 30, 1978*. Minneapolis: University of Minnesota, 1978.

Lenski, G. E. Status crystallization: A non-vertical dimension of social status. *American Sociological Review*, 1954, **19**, 405-413.

Lenski, G. E. Social participation and status crystallization. *American Sociological Review*, 1956, **21**, 458-464.

Lewis, M. *The culture of inequality*. Amherst: University of Massachusetts Press, 1978.

Lurie, O. R. Parents attitudes toward use of mental health services. *American Journal of Orthopsychiatry*, 1974, **44**, 109-120.

Maslach, C. Job burnout: How people cope. *Public Welfare*, Spring 1978, 56-58.

McCormick, M. *Enduring values in a changing society*. New York: Family Service Association of America, 1975.

Mehrabian, A. *Public places and private spaces: The psychology of work, play and living environments*. New York: Basic Books, 1976.

Merton, R. K. *Sociological ambivalence and other essays*. New York: Free Press, 1976.

Minnesota State Planning Agency. *CAIR: Community alternatives and institutional reform*. St. Paul, MN: State Planning Agency — Developmental Disabilities Program, January 1975.

Moroney, R. *The family and the state: Considerations for social policy*. London: Longmans, 1976.

Moroney, R. The need for a national family policy. *Urban and Social Change Review*, 1977, **10**, 10-14.

Moyer, K. Changing family structures for family initiated infant stimulation. Paper presented at the annual meeting of the American Association on Mental Deficiency, Portland, OR, May 1975.

Murray, M. A. Needs of parents of mentally retarded children. Reprinted from the *American Journal of Mental Deficiency*, May 1959, **63**(6).

Parad, H. J. (Ed.). *Crisis intervention: Selected readings*. New York: Family Service Association of America, 1965.

Perske, R. *New directions for parents of persons who are retarded*. Nashville: Abingdon Press, 1973.

Pless, I. B. *Individual and family needs in the health care of children with developmental disorders*. Chicago: Year Book Medical Publications, 1976.

Poznanski, E. O. Emotional issues in raising handicapped children. *Rehabilitation Literature*, 1973, **34**, 322-326.

President's Commission on Mental Health. *Report to the President*. Vol. I. Washington, DC: US Government Printing Office, 1978.

President's Committee on Mental Retardation. *Mental retardation: Century of decision*. Washington, DC: US Government Printing Office, 1976.

Ray, J. S. The family training center: An experiment in normalization. *Mental Retardation*, 1974, **12**(1), 12-13.

Rice, R. M. *American family policy*. New York: Family Service Association, 1977.

Robinson, N. M., & Robinson, H. B. *The mentally retarded child: A psychological approach* (2nd ed.). New York: McGraw-Hill, 1976.

Rodman, D. H., & Collins, M. J. A community residence program: An alternative to institutional living for the mentally retarded. *Training School Bulletin*, 1974, **71**, 52-61.

Ross, A. O. *The exceptional child in the family: Helping parents of exceptional children*. New York: Grune & Stratton, 1964.

Rushmer, R. F. *Humanizing health care: Alternative futures for medicine*. Cambridge: The MIT Press, 1975.

Saenger, G. *The adjustment of severely retarded adults in the community*. Albany: New York State Interdepartmental Health Resources Board, 1960.

Sager, A. Estimating the costs of diverting patients from nursing homes to home care. Paper presented at the 30th annual meeting of the Gerontological Society, November 1977.

Sammons, C. Ethical issues in genetic intervention. *Social Work*, May 1978, 237-242.

Sarason, S. B., Carroll, C. F., Maton, K., Cohen, S., & Lorentz, E. *Human services and resource networks*. San Francisco: Jossey-Bass, 1977.

Scheerenberger, R. C. *Public residential services for the mentally retarded, 1976*. Madison: National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1976.

Scheerenberger, R. C. *Public residential services for the mentally retarded*. Madison: National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1978.

Schield, S. The family of the retarded child. In R. Koch & J. C. Dobson (Eds.), *The mentally retarded child and his family: A multidisciplinary handbook*. New York: Brunner/Mazel, 1976.

Settles, B. H., Culley, J. D., & Van Name, J. B. *How to measure the cost of foster family care*. Washington, DC: US Department of Health, Education and Welfare (OHDS 77-30126), 1977.

Simmel, G. *The sociology of Georg Simmel*. New York: Free Press, 1950.

Skarnulis, E. Less restrictive alternatives in residential services. *AAESPH Review*, 1976, **1**(3), 40-84.

Skarnulis, E. Residential services: Support not supplant the natural home. Paper presented at the Southwestern Region Deaf-Blind Center, Special Study Institute, San Diego, CA, August 22, 1976.

Skelton, M. Areas of parental concern about retarded children. *Mental Retardation*, 1972, **10**(1), 38-41.

Skolnick, A. *The intimate environment: Exploring marriage and the family*. Boston: Little, Brown, 1978.

Special Committee on Aging, United States Senate. *Adult day facilities for treatment, health care, and related services*. Washington, DC: US Government Printing Office, 1976.

Srole, L., Langer, T. S., Michael, S. T., Opler, M. K., & Rennie, T. A. *Mental health in the metropolis*. New York: McGraw-Hill, 1962.

Sterner, R. *Social and economic conditions of the mentally retarded in selected countries*. Brussels: The International League of Societies for the Mentally Handicapped for the United Nations, Department of Economic and Social Affairs, 1976.

Sternlicht, M. Variables affecting foster care placement of institutionalized retarded residents. *Mental Retardation*, 1978, **16**(1), 25-28.

Stone, N. W. A plea for early intervention. *Mental Retardation*, 1975, **13**(5), 16-17.

Stonequist, E. V. *The marginal man*. New York: Charles Scribner's Sons, 1937.

Sussman, M. Family. In J. Turner, et al., (Eds). *Encyclopedia of social work*, Vol. I. New York: National Association of Social Workers, 1977, 357-368.

Thorsheim, M. J., & Bruininks, R. H. *Admission and readmission of mentally retarded people to residential facilities*. (Project Report No. 2). Minneapolis, MN: University of Minnesota, Developmental Disabilities Project on Residential Services and Community Adjustment, 1978.

Townsend, P. W., & Flanagan, J. J. Experimental preadmission program to encourage home care for severely and profoundly retarded children. *American Journal of Mental Deficiency*, 1976, **80**, 562-569.

Vitello, S. J. The institutionalization and deinstitutionalization of the mentally retarded in the United States. In L. Mann & D. A. Sabatino (Eds.), *The third review of special education*. New York: Grune & Stratton, 1976.

Willer, B. Post institutional adjustment of the retarded returned to the natural families. Paper presented at annual convention of American Association on Mental Deficiency, May 19, 1978.

Willer, B., & Intagliata, J. *Evaluation of the impact of deinstitutionalization on the mentally retarded, their families and the community*. Unpublished manuscript, 1978.

COMMUNITY LIVING FOR THE HANDICAPPED, INC.

NAME AND ADDRESS OF ORGANIZATION:

Community Living for the Handicapped, Inc.
145 South 5th Street
P.O. Box 997
St. Charles, Missouri 63301
(314) 724-4336
Contact: Wes Erwin

SPONSOR/BASIS:

State of Missouri, Senate Bill 359

PURPOSE OF PROJECT/PROGRAM:

To provide a continuum of services for the developmentally disabled and their families in St. Charles County, Missouri.

SERVICES PROVIDED:

1. Day Activity Center - for those age 16 and older; 2. Respite Care Home—for any age individual; 3. Residential Group Homes—for those age 16 and older; 4. Apartment Living—for those age 16 and older.

ELIGIBILITY:

Any developmentally disabled individual and/or families of the developmentally disabled. Age requirements vary depending upon the services used.

PILOT PARENTS PROGRAM

NAME AND ADDRESS OF ORGANIZATION

Pilot Parents Program
Greater Omaha Association for Retarded Citizens
3212 Dodge Street
Omaha, Nebraska 68131
(402) 348-9220
Contact: Patty Smith

SPONSOR/BASIS:

Greater Omaha Association for Retarded Citizens
Region VII Developmental Disabilities Grant

PURPOSE OF PROJECT/PROGRAM:

The Pilot Parents Program is a program in which parents of handicapped children help parents who have recently learned that their child has mental retardation, cerebral palsy, epilepsy, or autism.

SERVICES PROVIDED:

Pilot Parents offer:

- emotional support and understanding
- factual information about medical services, educational programs, and supportive agencies
- introduction to helpful persons and groups that share their interests and concern.

Pilot Parents believe that offering emotional support and factual information about a child's handicap enables parents to view, in a positive manner, their child's ability to grow, learn, and develop to his fullest potential.

ELIGIBILITY:

The Pilot Parents Program serves parents of all children with developmental disabilities.

PENNSYLVANIA DEPARTMENT OF PUBLIC WELFARE

OFFICE OF MENTAL RETARDATION

NAME AND ADDRESS OF ORGANIZATION:

Department of Public Welfare
Office of Mental Retardation
411 Health and Welfare Building
Harrisburg, Pennsylvania 17120
(717) 7887-5102

Contact: Art Geisler

SPONSOR/BASIS:

State of Pennsylvania
90% state funds
10% local matching funds

PURPOSE OF PROJECT/PROGRAM:

To provide families of the mentally retarded with support services to enable them to maintain their family members in the community.

SERVICES PROVIDED:

1. Respite Care — provides temporary residence for the retarded person when the family or legal guardian is experiencing stress, personal crises or needs a vacation.
2. Family Aid Sitter Service — for parents who need a person to care for their retarded family member for a few hours at a time. This service gives the family the opportunity to participate in normal activities (i.e., shopping, religious worship, school and civic meetings).
3. Homemaker Services — a homemaker may be available to perform essential household duties when family members or the individual are unable to manage such tasks effectively. This type of service may be to maintain continuity of care of a mentally retarded person within the home during a family illness or similar circumstance or to provide training in proper home management for the retarded person or his/her family or legal guardian with whom he/she resides.
4. Transportation — may be offered to families or individuals who need assistance in transporting themselves, children or adult family members to regular day programs or appropriate activities.
5. In-home Therapy — this service insures that the retarded family member will receive the necessary treatment or therapy even when he/she is homebound. Included are: visiting nurse, physical therapist, occupational therapist, speech therapist, language therapist, audiologist, visual mobility therapist, vocational therapist, recreational therapist, dental hygienist, and behavior management specialist.
6. Family Education and Training — these programs may be offered to assist parents of a retarded child or adult, retarded individuals are parents, spouses, and sibling, or other family members (i.e., grandparents, aunts, uncles, etc.) in dealing appropriately with a family member who is mentally retarded. This may include education/training in family dynamics, parent/child relations, behavior management, genetic counseling, family planning, or any other type program designed to maintain the family as a cohesive unit.
7. Recreation/Leisure Activities — recreation services allow the retarded person to experience normative community leisure time activities and increase his/her ability to participate more independently in similar activities. The family may

benefit by having periods of relief by knowing that the retarded person is engaging in appropriate social recreational activities which will enhance his/her physical and psychosocial growth and development.

8. Special Innovative Services — these opportunities may be funded with FRS funds provided that they conform to the definitions and intent of FRS regulations.

ELIGIBILITY:

All mentally retarded individuals living in the community setting and their families.

CATHOLIC CHARITIES DISABILITY SERVICES

NAME AND ADDRESS OF ORGANIZATION:

Catholic Charities Disabilities Services
2451 Country Club
Stockton, California 95204
(209) 466-3685

Contact: Ken Schwarzentraub

SPONSOR/BASIS: State of California

Department of Health
Appropriation — $37,000 — Case Management Project
$20,000 — Behavioral Intervention Services Project
$40,000 — Respite Care Project

PURPOSE OF PROJECT/PROGRAM:

1. Prevention of institutionalization
2. Deinstitutionalization
3. In-home support services

SERVICES PROVIDED:

1. Case Management — all-purpose backup person, support person. Steps in providing service: acquire diagnostic information from medical team; perform a functional assessment; design with the family and child an individual program plan (IPP); case manager enters the community to find the services which fulfill the IPP; manager obtains the money for the objective stated in the IPP; purchase of services; evaluation; if upon evaluation the individual is at a plateau, the manager examines possible reasons why and makes appropriate changes; if the individual has not progressed a new program plan is developed.
2. Behavioral Intervention Services — Community-based behavior modification services. Intervention workers go to the homes or schools and diagnose particular inappropriate behaviors, i.e., self-abusive behavior, inappropriate sexual behavior, toilet training behavioral problems, inappropriate social responses.
3. Respite Care — Sitter Service
   Within this project, trained personnel are recruited and screened. Approximately 20 hours of respite care service are purchased for a family.

ELIGIBILITY:

The services are available to the general public provided they pay fees. For referrals made by the regional centers, funding is provided for the client.

MR — Family Subsidy Program, Department of Public Welfare — Mental Retardation Division

NAME AND ADDRESS OF ORGANIZATION:

MR — Family Subsidy Program
Minnesota State Department of Public Welfare
Centennial Building
St. Paul, Minnesota 55155
(612) 296-4977

Contact: Cristy Boswell

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SPONSOR/BASIS:

State of Minnesota
Direct State Legislative Appropriation
Minnesota Statutes, Section 252.27, Subdivision 4

PURPOSE OF PROJECT/PROGRAM:

To determine the effectiveness of the family unit in providing alternate living arrangements and to provide or arrange for the training and the developmental opportunities not provided in a state hospital or a licensed community residential facility. . . an experimental program subsidizing selected families who agree to carry out a planned program at home and providing training for their minor dependents who are mentally retarded.

SERVICES PROVIDED:

Subsidies not to exceed $250/month are made to families within the Guidelines for Reimbursable Expenses and subject to approval by the Project Coordinator.

ELIGIBILITY:

"This program shall be limited to children who otherwise would require and be eligible for placement in state hospitals or licensed community residential facilities."

WEEK-END CARE FOR MENTALLY RETARDED IN RURAL COMMUNITIES.

NAME AND ADDRESS OF ORGANIZATION:

Day Developmental Training Program Division of Mental Retardation
P.O. Box 44215
721 Government Street
Baton Rouge, La. 70804
(800) 252-9014

Contact: Lola Busenbarrick

SPONSOR/BASIS:

"Louisiana Office of Mental Retardation contracts with local community organizations to provide Day Developmental Training Programs." "The Week-end Parent Relief Pilot Program presently offered at three centers is funded through a grant from the Regional Developmental Disabilities Office."

PURPOSE OF PROJECT/PROGRAM:

Objectives of the program are:

1. To provide relief to parents of mentally retarded individuals who reside in rural areas by offering short term respite care on weekends through the local Day Developmental Training Center.
2. To offer an outlet for social and emotional needs of retarded individuals through participation in the week-end respite care program.
3. To increase public awareness and understanding of the developmentally disabled through the use of volunteers providing recreational opportunities to participants in the week-end respite care program.
4. To initiate a program of short term respite care, not only to provide a needed service, but to gather supportive data to be used in conjunction with appropriation requests to the state legislature; it is the expectation that this proposed program should become an integral part of services to families and retarded individuals who live in the community, rather than in an institution.

SERVICES PROVIDED:

Providing weekend services to families of handicapped individuals which will:

- provide an opportunity for families of handicapped individuals to live fuller and more normalized lives
- reduce need or concern for institutionalization of handicapped individuals

- allow developmentally disabled individuals to enhance their development in their regular day developmental training program
- lead to an increased understanding of and concern for the developmentally disabled.

ELIGIBILITY:

Families of mentally retarded individuals. Individuals using the service range in age from babies to adults, although mainly adults use this service.

SONOMA COUNTY AGENCY FOR INFANT DEVELOPMENT, INC.

NAME AND ADDRESS OF ORGANIZATION:

Sonoma County Agency for Infant Development, Inc.
1741 4th St.
Santa Rosa, California 95404
(707) 545-0213

Contact: Sue Powell

SPONSOR/BASIS:

No sponsor. Self-directed and operated, non-profit organization.
North Bay Regional Center (state agency) — 80%
United Way — 5%
Donations and fund raisers — 15%
Appropriation — $82,775.00

PURPOSE OF PROJECT/PROGRAM:

"To assist families in keeping the children in private homes during their greatest growing time, and thus avoid the need for institutionalization and subsequent lack of necessary training."

SERVICES PROVIDED:

Home visiting agency serving children in their homes; mother and baby groups at the agency are provided — mothers have discussion groups while agency members work with babies downstairs. One father has started a fathers' discussion group also.

ELIGIBILITY:

Any family in Sonoma County with a child from birth to age three, with developmental disabilities, is eligible.

BUREAU OF DEVELOPMENTAL DISABILITIES — CASE SERVICE SECTION. DEPARTMENT OF SOCIAL AND HEALTH SERVICES.

NAME AND ADDRESS OF ORGANIZATION:

Bureau of Developmental Disabilities - Case Service Section
Department of Social and Health Services
Olympia, Washington 98508
(206) 753-1447

Contact: Barbara Hough

SPONSOR/BASIS:

State of Washington
69% Title 20 federal monies
31% state funds
Appropriation — '77-'78 $493,000.00
'78-'79 $517,000.00

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PURPOSE OF PROJECT/PROGRAM:

Services are given in order to reduce or eliminate the need for out-of-home residential placement and to allow the client to reside in the least restrictive environment by:

1) strengthening the family as a primary resource,
2) stabilizing or developing a preferred living situation,
3) increasing individual independence.

SERVICES PROVIDED:

- respite care in and out of the home
- extended care (short term, day care-type service for single parents)
- resource therapies
- parent to parent outreach

ELIGIBILITY:

Individuals who are eligible for bureau services; also provided when no other resource is available (i.e., private or local or other department resources) in the community. Services are delivered in accordance with an individual's IPP (individual program plan).

SOMERSET HOME SCHOOL

NAME AND ADDRESS OF ORGANIZATION:

Somerset Home School
7030 Grant Ave.
Carmichael, California 95608
(916) 944-0540

Contact: Thomas Whalley

SPONSOR/BASIS:

State of California — 66% in connection with SSI.
Federal monies — 33%
Appropriation — $159,912.00

PURPOSE OF PROJECT/PROGRAM:

To stabilize the profoundly handicapped child and integrate him with his family at whatever level they are capable of handling.

SERVICES PROVIDED:

Residential care with physical therapy, feeding techniques, hydrotherapy, music and art, within the context of family living.

ELIGIBILITY:

Any family whose child is profoundly physically and mentally handicapped between the ages of birth and 6 years.

VALLEY MOUNTAIN REGIONAL CENTER

NAME AND ADDRESS OF ORGANIZATION:

Valley Mountain Regional Center
850 N. Hunter St.
Stockton, California 95202
(209) 948-0636

Contact: Jim Austin

SPONSOR/BASIS:

Lanterman Act #3600
State of California
Appropriation — $2.6 million

PURPOSE OF PROJECT/PROGRAM:

To provide services and counseling for families and individuals who are developmentally disabled.

SERVICES PROVIDED:

1. Diagnostic
2. Case management
3. Purchase of services for developmentally disabled, e.g., tuition for program participation

ELIGIBILITY:

Anyone determined to be developmentally disabled and diagnosed as such before the age of 18 yrs.

ALABAMA UAF EARLY INTERVENTION PROGRAM

NAME AND ADDRESS OF ORGANIZATION:

Alabama UAF Early Intervention Program
Box 313 University Station
Birmingham, Alabama 35294
(205) 934-4871

Contact: Joan Bergman

SPONSOR/BASIS:

University of Alabama — Birmingham
State of Alabama — 25%
Federal — 75%
Appropriation — $190,000.00

PURPOSE OF PROJECT/PROGRAM:

The development of tools to be used in service. Any services are designed to field test tools or learn more about what the program is doing.

SERVICES PROVIDED:

1. Development of tools for use/or treatment models for either sophisticated professionals, parents, or to aid people. E.g., visual aid tools for people in visual field; visual aid in instruction.
2. Field testing the tools
3. In the past, advanced University students have been used in communications, physical therapy, and teaching of a wide variety of things to lower level students.
4. Workshop on symbols in communication.
5. Teach through others' workshops.

ELIGIBILITY:

Profoundly retarded individuals are eligible, although no direct work is done with families.

REGIONAL CENTER OF ORANGE COUNTY, INC.

NAME AND ADDRESS OF ORGANIZATION:

Regional Center of Orange County, Inc.
500 Main St. S.
Orange, California 92668
(714) 973-1999

Contact: Nancy Bradley

SPONSOR/BASIS:

State of California — 97%
Federal — 3%
Lanterman legislation revised — 1977
Appropriation — $6,000,000.00

PURPOSE OF PROJECT/PROGRAM

1. Mandated to provide diagnostic evaluation and develop an individual program plan for every client eligible for services;
2. Program may purchase services for those persons.

SERVICES PROVIDED:

1. Case manage those persons receiving various program services.
2. Diagnostic evaluations.
3. Community program development.

ELIGIBILITY:

Mentally retarded, cerebral palsied persons - diagnosed developmentally disabled prior to the age of 18 yrs, and in need of services similar to those who are retarded; individuals must be substantially handicapped.

NASHVILLE REGIONAL INTERVENTION PROGRAM

NAME AND ADDRESS OF ORGANIZATION:

Nashville Regional Intervention Program
2400 White Ave.
Nashville, Tennessee 37204
(615) 269-5671

Contact: Vince Parrish

SPONSOR/BASIS:

State of Tennessee — 100%
Appropriation — under $50,000.00

PURPOSE OF PROJECT/PROGRAM:

To have mothers train their children and modify both their own behavior where necessary and their children's behavior.

SERVICES PROVIDED:

1. Diagnostic
2. Physical therapy
3. Classes teaching interactive behavior
4. Mother/child sessions
5. Visiting consultants set up programs
6. Resource people are available

ELIGIBILITY:

Developmentally disabled individuals are eligible for service up to the age of five years.

TRI-COUNTY REGIONAL CENTER INTENSIVE BEHAVIORAL INTERVENTION CENTER

NAME AND ADDRESS OF ORGANIZATION

Tri-County Regional Center
22 West Michel Torena
Santa Barbara, California 93101
(805) 963-6717

Contact: Michael Mahoney

SPONSOR/BASIS:

State of California — 100%
Appropriation — $600,000.00

PURPOSE OF PROJECT/PROGRAM:

Handle crises; keep clients in the least restrictive environment; act as intermediary and create direct programs.

SERVICES PROVIDED:

Direct service: behavioral therapy

ELIGIBILITY:

Individuals who are developmentally disabled according to the State of California definition, and whose disability occurred before the age of 22 years.

CENTER FOR THE DEVELOPMENT OF COMMUNITY ALTERNATIVE SERVICE SYSTEMS (CASS) — RESPITE SERVICES COMMUNITY DEVELOPMENT PROJECT

NAME AND ADDRESS OF ORGANIZATION:

Center of Development of Community Alternative Service Systems (CASS)
Box 118, U.N.M.C.
4300 Emile Street
Omaha, Nebraska 681313
(402) 541-7717

Contact: Bertine Loop — Coordinator; Respite Services Community Development Project

SPONSOR/BASIS:

Grant from the Developmental Disabilities Office in HEW
Appropriation — $75,000.00

PURPOSE OF PROJECT/PROGRAM:

To provide information and technical assistance which will facilitate community-based respite services. These services in turn will: (1) provide to families with developmentally disabled family members the temporary supports and services needed to maintain the family system; and (2) prevent the need for out-of-home-residential services.

SERVICES PROVIDED:

1. Identification of representative respite services programs that could serve as resources for replication and adaptation for other communities.
2. Develop step-by-step "how to" planning and implementation manuals for respite service systems for use by consumer groups, service agencies, D.D. Councils, etc.

3. Assist identified communities in the development of respite service systems, in a model specific to their individual needs and resources.
4. Develop on-going systematic technical assistance mechanisms for DD Councils, community service agencies and consumer groups, to aid in their planning for community respite services.
5. Make specific recommendations related to legislative priorities and fiscal resources to support community respite service systems.

ELIGIBILITY:

Not a direct service organization; rather, focus is on research and application.

EARLY CHILD INTERVENTION

NAME AND ADDRESS OF ORGANIZATION:

Early Child Intervention
Teaching Research
Monmouth, Oregon 97361
(503) 838-1220

Contact: Bud Fredericks

SPONSOR/BASIS:

State and Federal monies
Appropriation — $150,000.00

PURPOSE OF PROJECT/PROGRAM:

The purpose of this project is to provide training for parents so that they might: 1) teach their own children skills they feel a child needs to learn, or 2) be given procedures to help remedy behaviors that might need to be corrected. This is conducted on an individual basis. Parents are responsible for identifying children needing training.

SERVICES PROVIDED:

1. Develop training models
2. Train people to service the counties
3. Provide continual in-service training by periodically visiting them in the counties, critiquing their work and functioning as a resource service
4. Functioning as a prescriptive program for children not responding to parent assistance within the home

ELIGIBILITY:

Any family that has a developmentally disabled child is eligible. Children as well as adults are provided with services, e.g., group homes and foster parents.

CENTER ON HUMAN DEVELOPMENT

NAME AND ADDRESS OF ORGANIZATION:

Center on Human Development
University of Oregon
Eugene, OR 97403
(513) 686-3575

Contact: Robert Schwartz
William Fink
Anita Crosson
Thomas Bellamy

SPONSOR/BASIS:

University of Oregon
State of Oregon — 100%
Appropriation — $3,000,000.00

PURPOSE OF PROJECT/PROGRAM:

To assist the developmentally disabled in achieving their full potential.

SERVICES PROVIDED:

1. Direction Center: find services for parents within the community when the University's Center cannot help them;
2. Legal advocacy team: work with parents;
3. Five direct training classes within the Center for developmentally disabled who are either pre- or post-school age;
4. Assistance to public schools in aiding school-age children
5. Act as an advocate for parents of new-borns.
6. Diagnostic services
7. Work programs in business and teach adults work skills
8. Pre-schooler training

ELIGIBILITY:

Anyone with a handicapped individual in the family in need of services.

OREGON PROJECT — REPLICATION

NAME AND ADDRESS OF ORGANIZATION:

Oregon Project
Department of Public Welfare
Centennial Office Building
St. Paul, Minnesota 55155
(612) 296-3250

Contact: Zetta Feder

SPONSOR/BASIS:

State of Minnesota — 100%

PURPOSE OF PROJECT/PROGRAM:

This replication of the Oregon Project is to get children out of so-called "temporary foster care," to reduce the length of stay, and to find permanent homes for them.

SERVICES PROVIDED:

Workshops are provided to introduce other counties to the strategies used in the Oregon Project.

ELIGIBILITY:

Any foster child, developmentally disabled or "normal" child is eligible for service.

THE TROUBLE SHOOTERS

NAME AND ADDRESS OF ORGANIZATION:

The Trouble Shooters
1600 W. Armory Way
Seattle, WA 98119
(207) 284-1037

Contact: Pat Roberts

SPONSOR/BASIS:

Federal Law under the Developmental Act
Dept. of Health, Education and Welfare and private foundations provide monies
Appropriation — $175,000.00

PURPOSE OF PROJECT/PROGRAM:

The purpose of the program is to teach parents and the handicapped to be advocates for themselves. The aim of the program is to protect the handicapped and their families against private and system problems while educating them.

SERVICES PROVIDED:

1. Referral service - located in most counties of the state
2. Education programs
3. Advocacy role

ELIGIBILITY:

Any handicapped individual, not restricted to developmentally disabled individuals.

SITTER SERVICE FOR THE HANDICAPPED

NAME AND ADDRESS OF ORGANIZATION:

Sitter Service for the Handicapped
3035 G Street
San Diego, CA 92102
(714) 234-2264

Contact: Mary Jim Martin

SPONSOR/BASIS:

A respite service of the San Diego County Association for the Retarded

PURPOSE OF PROJECT/PROGRAM:

The purpose of the program is to provide in-home relief to parents or caretakers of handicapped persons on a temporary basis, making it possible for family stability to be maintained.

SERVICES PROVIDED:

A trained sitter is available for overnight or temporary service as needed to care for the handicapped member in the surroundings of his/her home.

The sitters are trained in the following areas:

— Feeding
— Toileting
— Behavior management
— Seizure first aid
— Dressing
— Non-verbal communication
— Use of adaptive equipment.

ELIGIBILITY:

Any family, with an individual with any handicap and of any age, is eligible for service.

BRONX DEVELOPMENTAL PROGRAM

NAME AND ADDRESS OF ORGANIZATION:

Bronx Developmental Program
c/o Rose F. Kennedy Center
1410 Pelham Parkway South
Bronx, New York 10461

Contact: Dr. Herb Cohen

SPONSOR/BASIS:

Mental Hygiene Law
State Department of Hygiene monies - 100%

PURPOSE OF PROJECT/PROGRAM:

The purpose of this program is to provide home-like settings in the community for mentally retarded individuals.

SERVICES PROVIDED:

1. Monitor foster care settings
2. Monitor individual cases
3. Broad range of services

ELIGIBILITY:

Developmentally disabled individuals are eligible, but essentially all are mentally retarded.

Appendix B

Annotated Bibliography

ANNOTATED BIBLIOGRAPHY

These publications comprise those which were found by formal and informal search of current literature relating to family care of developmentally disabled members. The content of each annotation is intended to very briefly describe the publication, and in most cases is not an author's abstract.

Abeson, A. & Boleck, N. *A continuing summary of pending and completed litigation regarding the education of handicapped children.* Reston, VA: Council for Exceptional Children, December, 1974.

This journal article has organized a summary of relevant litigation regarding the right of handicapped children to equal protection under the law—including being provided with an education and full rights of notice and due process in relation to their selection, placement, and retention in educational programs.

This summary does not include all cases filed to date, since new information is continually being received about existing new cases.

Allen, R. M. & Cortazzo, A. D. *Psychosocial and educational aspects and problems of mental retardation.* Springfield: Charles C. Thomas, 1970.

In this book, the authors discuss the psychological, social and educational issues involved in the identification, evaluation, education, training, and counseling of the retarded child. The authors have covered such topics as: the changing concepts of mental retardation; an identification of the condition; the attempts to redefine and classify mental retardation; mode of evaluating the retarded child's functioning; relationship between school and the child; history of the development of the educational needs of the retarded child and how they may be met; roles parents play in the development of the retarded child; and concerns of the post-school retarded child.

Although the book does not deal specifically with family care programs, it does offer valuable information concerning parental attitudes and problems in dealing with their retarded children.

Allen, S. V. et al. *Perspectives on child care.* Washington, DC: National Association for the Education of Young Children. Taken from E. V. Loon & L. Levy, *Inequality in education.* Cambridge: Harvard Center for Law and Education, 1972.

This issue seeks to lend some perspective to the growing national debate on whether a major investment of federal funds in new child care legislation is warranted. In an attempt to answer many questions related to this topic, various articles are presented which deal with the cost, legislation, opposition and problems associated with child care programs.

No programs designed to aid in the family care of developmentally disabled individuals were discussed.

Barnard, K. E. & Powell, M. L. *Teaching the mentally retarded child: A family care approach.* St. Louis: The C. V. Mosby Company, 1972.

This book is directed to the care of the handicapped child in infancy and early preschool years who lives with his family. This period is seen as critical in relation to the child's development of skills and independence, as well as for promoting the healthy adjustment of the parents and other family members to the problems of a handicapped child.

The book presents the information, the rationale, and the process the authors used to work with handicapped children and their families.

Baronyay, E. P. *The mentally handicapped adolescent.* New York: Pergamon Press, 1971.

This book reviews the aims and achievements of the Slough Project of the National Society for Mentally Handicapped Children. The Project was concerned with community care of mentally retarded adolescents. The book examines prevailing conditions leading to development of the scheme and details of the scheme. The study concludes with a review of the achievements of the Project and thoughts on future planning.

The book provides no information regarding family care of developmentally disabled individuals.

Battle, C. U. & Ackerman, H. C. *Early identification and intervention programs for infants with developmental delay and their families: A summary and directory.* Chicago: National Easter Seal Society for Crippled Children, 1973.

This directory and report are the products of a program survey conducted for a threefold purpose: (1) to compile and publish descriptions of existing programs so that such information, not readily available, could be shared with persons intending to initiate similar programs; (2) to encourage Easter Seal Societies and others concerned with early identification and infant development to initiate appropriate programs in their communities; and, finally, (3) to develop a document for use by participants in a conference for allied health professionals.

The major findings of the survey are reviewed and a summary of each program is presented.

Programs were deliberately excluded which did not deal specifically with infants under three years of age.

Numerous programs are listed dealing with both the parents and the child with developmental delay, although programs designed to aid family care of developmentally disabled individuals were not specifically mentioned.

Beck, H. L. *Social services to the mentally retarded.* Springfield: Charles C. Thomas, 1969.

The author discusses needs of the retarded individual, the family, and the community, plus the special need for a well-integrated interdisciplinary approach, the need to counteract fragmentation and/or over-servicing as a result of such an approach, and the need for a variety of social services to meet the many aspects of social problems of import in this condition.

Ways of meeting these needs are considered with a view to the services rendered by the different disciplines involved, and with special consideration of the role of the social worker.

A few chapters deal very generally with services available to the retarded and their families. For the most part there is a focus on the role of the social worker in dealing with the retarded and his/her family. Specific programs for family care are not mentioned.

Carver, J. N. & Carver, N. E. *The family of the retarded child.* Syracuse: Syracuse University Press, 1972.

This book deals with a group of parents' response to having severely retarded children: the aspects of their family behavior that had been affected, how severe the effects were, specific experiences which were crucial for them, and how they felt about these experiences. Many of the chapters deal with how the functioning of the family was affected or modified by the retarded child's behavior and presence in the home.

Although specific family care programs are not dealt with, much information is provided about the short term and long range needs of and problems encountered by the family.

Conley, R. W. *The economics of mental retardation.* Baltimore: The Johns Hopkins University Press, 1973.

The book surveys the epidemiology of mental retardation: its causes, the demographic characteristics, the prevalence of mild and severe retardation, and the

physical and behavioral handicaps of the retarded. Also included is an analysis of the existing programs designed to integrate the mentally retarded into society and a cost-benefit analysis of rehabilitative, educational, institutional, and preventive services.

The author concludes that the present services offered to the mentally retarded constitute an unbalanced program. He suggests an optimal program consisting of a wide range of services designed to render a broad variety of treatment and prevention.

Dunlap, W. R. Services for families of the developmentally disabled. *Social Work*, 1976, *21*, 220-223.

This article deals with services for families of the developmentally disabled. It discusses the findings of a 1973 survey by the University of Alabama of the developmentally disabled of that state. Specifically, it examines which social services are needed and which are actually used by developmentally disabled persons and their families.

Emlin, A., Lahti, J., Downs, G., McKay, A. & Downs, S. *Overcoming barriers to planning for children in foster care*. Portland, OR: Portland State University, 1977.

This report describes the Oregon Project's activities at the state level and in selected counties. It describes the problems, clients, efforts made and by whom, social work and legal components, process, cost, savings, and successes encountered in working with the state agency to remove barriers to permanent planning.

In achieving permanent homes for foster children, the authors emphasize that this can only be accomplished with: 1) structured, time-limited rehabilitation programs for parents to help reunite families; 2) early intervention from the time the child first enters foster care; 3) planned regular visits between parents and child; 4) decisiveness about the best future placement for the child; 5) knowledge of how to work with the courts to terminate parental rights; and 6) a range of placement options based on agency policy and statutory authorization. These should include subsidized adoption, formalized long-term foster care agreements, and guardianships.

The report provides insight into such matters as case screening and management techniques; use of appellate decisions, statutes, and specific legal decisions; cost effectiveness; and available funding sources.

This volume is available from the Permanent Planning Project, Regional Research Institute for Human Services, Portland State University, PO Box 751, Portland, OR 97297 (no charge).

Farber, B. Family adaptations to severely mentally retarded children. In M. J. Begab & S. A. Richardson, *The mentally retarded and society: A social science perspective*. Baltimore: University Park Press, 1975.

Farber discusses some assumptions regarding the adaptational process to problematic family situations. He first presents the principle of minimal adaptation as a basis for ordering changes in family relationships. In the analysis of change in family interaction, he cites various alternative assumptions about the choice of adaptations about family members. First possible assumption: adaptations are capricious and depend mainly upon the power structure of the family. A second, alternative assumption is to regard the adaptational process as a "rational means for attaining ends in family life." A third assumption, which is explored in the paper, is that of minimal adaptation. This assumption implies that families will make as minimal an adaptation as possible to solve problems involving family relationships.

Franklin, P. A. *Impact of disability on the family structure*. Social Security Bulletin. Washington, DC: Social Security Administration, US DHEW, May 1977.

The Social Security Administration survey of the disabled and nondisabled in 1972 provides data on the self-reported behavior of the two groups; the data are useful in examining the impact of disability upon individuals and their families. This article contrasts the behavior and family patterns of these two segments of the population with regard to marital status, stability of marriages, and household or financial assistance provided by extended family members. In addition, it includes a

description of the nuclear family's contraction of activities and participation in various aspects of living.

Frost, F. At risk! *Childhood Education*, 1975, 51, 298-304.

This article supplies its readers with an overview of significant research on intervention programs for high risk infants and young children. Also included is the rationale for family oriented intervention.

Gliedman, J. & Roth, W. *Handicapped children in America* (working title). New York: Academic Press, forthcoming.

An intensive and extensive exploration of what it means to be a handicapped child, what we know and what we do not know, and what we should do. Chapters on sociology, psychology, economics, medicine, special education, and institutionalization.

Henney, L. R. (ed). Model programs in HEW regions IX-X for developmental disabilities. Monograph No. 1. December 1977.

This monograph is the first of a series made possible by the Bi-Regional Training and Technical Assistance Program. The objective of the Monograph Service is to create a forum whereby model programs and significant issues in developmental disabilities may be shared nationally.

The four monographs which will be published during fiscal year 1978 will feature:

—Monographs 1-3 will be Model Programs in Regions IX and X

—Monographs 2-4 will be Significant Issues in Developmental Disabilities.

The model programs are divided into three categories:

1) Programs of Internal Training and Technical Assistance for the Development of a Developmental Disabilities Planning Council.
2) Programs in which the Developmental Disabilities Planning Council Performs Training and Technical Assistance.
3) Direct Service Programs for the Benefit of Individuals with Developmental Disabilities.

Henrich, E. & Kriegel, L. *Experiments in survival*. New York: Association for the Aid of Crippled Children, 1961.

Henrich and Kriegel have put together a series of biographical sketches of various handicapping conditions. The contributors were asked to speak candidly about their handicaps and their experiences: origins, the encounter, education and afterward, and family and friends. Individuals present personal attitudes towards their handicaps.

Honig, A. *Parent involvement in early childhood education*. Washington, DC: National Association for the Education of Young Children, 1974.

This article supplies an up-to-date account of the varieties of programs which are oriented toward family involvement.

Howard, N. Day care: *An abstract bibliography*. Urbana: University of Illinois, 1974.

This bibliography includes references to both family and center day care, staffing and training programs.

Jew, W. Helping handicapped infants and their families: The delayed development project. *Children Today*, 1974, *3*, 7-13.

This article describes the Developmental Disabilities Project, San Joaquin County, California.

Koch, R. & Dobson, J. C. (eds.). *The mentally retarded child and his family: A multidisciplinary handbook*. Revised edition. New . York: Brunner/ Mazel Publishers, 1971.

Comprehensive volume for professionals and students in the many disciplines concerned with the mentally retarded child.

The encyclopedic volume draws upon the talents of 26 experts from 14 different disciplines to present a completely integrated and highly practical guide.

The sections covered are:

I. Introduction to the Problem of Mental Retardation

II. Biological Factors in Causation of Mental Retardation

III. The Multidisciplinary Approach to Mental Retardation

IV. Psycho-Social Aspects of Mental Retardation

Lillie, D. L., Trohanis, P. L. & Gorn, K. W. (eds.). *Teaching parents to teach*. New York: Walker & Company, 1976.

This book offers a framework for planning, organizing and implementing parental involvement activities in early childhood programs.

Included is a four-part discussion of parent programs: 1) an overview to parent programs; 2) the scope; 3) the operation; and 4) the resources for parent programs.

Four parent program models are reviewed within the section, Operation of Parent Programs. Specifically, a Center-Based Parent-Training Model; a Home-Center-Based Parent-Training Model; a Home-Based Parent-Training Model; and a Parent-Implemented Preschool Program are described.

Also included is an annotated bibliography of the Resources for Parent Programs.

Loop, B. *Center for the Development of Community Alternative Service Systems, Respite Services Community Development Project*. Omaha, NE: CASS, 1978.

Included in this manual are descriptive materials regarding the Respite Services Community Project. The purpose of the project is to assist in the development of integrated community-based respite service systems for developmentally disabled persons and their families. More specifically, the Project has focused on the development of community-based respite services from the perspective of the total community. The Project emphasizes programs that are individualized and responsive to the needs of consumers and their families.

The Project is currently in the second and final year of funding. The first-year activities focused on the identification and review of established community-based respite service programs. During the second year the Project is following up with current programs as well as further identification of additional respite services programs.

At present, three "how-to" manuals and other supportive resource materials are being prepared. Completion and use of these materials is set for October, 1978.

Mamula, R. A. *Developing a training program for family caretakers*. Springfield: Charles C. Thomas, 1973.

This paper discusses the rationale behind the development of a training program for individuals providing foster care services for mentally retarded and emotionally disturbed children and adults within the structure of the Family Care Program operated by the Community Services Division of the State of California. It discusses program development, content and effectiveness, and offers general guidelines for agencies interested in such programs.

Minnesota State Planning Agency. *CAIR - Community Alternatives and Institutional Reform*. St. Paul, 1975.

A portion of this document describes Parent-Support Programs which have existed and/or currently exist in a limited number of states. Most of these programs train parents to work with their developmentally disabled child. Some programs also provide social casework services, direct counseling, referral to community agencies, and general moral support.

It also mentions a reimbursement program which would provide parents with a fixed dollar amount with which to procure required services; this program became the Minnesota Family Subsidy Program.

A general desire expressed throughout the document is that parents be informed about community-based facilities and that accountability systems be developed so that parental fears can be dispelled.

Minnesota State Planning Agency—Developmental Disabilities Planning Office. *Public information and developmental disabilities.* St. Paul, 1977.

Minnesota's public information feasibility study proposed to summarize and interpret existing knowledge in order to form a basis for planning an effective developmental disabilities public information program in Minnesota. The review of literature focused on the following areas:

1. Attitude studies reporting the way people in this country view physical and mental disabilities generally;
2. Attitude studies reporting the way people in this country view developmental disabilities specifically;
3. Public information programs in the human services area generally; and
4. Public information programs in the developmental disabilities area specifically.

Although there was no mention of programs designed to aid in the family care of developmentally disabled individuals, specific support services (i.e., public information programs) available to the developmentally disabled were outlined.

Office of Economic Opportunity. *Catalog of federal domestic assistance.* Washington, DC: US Government Printing Office, 1969-0-328-264.

This catalog provides a comprehensive listing and description of 58 domestic assistance programs and activities administered by 47 federal departments and agencies. The catalog aids in identifying types of assistance sought and guides readers on how to apply specific types of assistance.

The catalog includes information on various forms of assistance available to state and local governments, to public and private business and industry, and to individuals.

No programs designed to aid in the family care of developmentally disabled individuals were specifically mentioned. However, support services which could be helpful are listed.

Office of Regional Director DHEW, Region V. *Alternatives to institutional care.* Chicago, July 1977.

This material was compiled by a Region V DHEW Task Force on Alternatives to Institutional Care in order to illustrate the overlap in client service needs and the multitude of federal agencies responsible for meeting these needs. The client categories used reflect present modes of functioning and define services and potential funding sources.

Also included is a lengthy list of federal agencies; it has implications for all levels of service delivery: the need for federal coordination, the time involved when state and local agencies attempt to fund and/or run a program.

Pike, V., Downs, S., Emlen, A., Downs, G., & Case, D. *Permanent planning for children in foster care: A handbook for social workers.* Portland, OR: Portland State University, 1977.

The handbook is designed to assist social workers in developing permanent plans for children in foster care.

It begins by presenting the basic philosophy and framework of the Oregon Project and continues with the step-by-step procedures for assessing barriers to permanent planning, for developing treatment plans, for choosing alternatives, and for terminating the parent-child relationship.

The handbook is a practical reference for analyzing available placement options and for selecting an appropriate plan to permanence. Specifically, the handbook contains:

—decision trees at the beginning of each chapter depicting which decisions are made, when, and by whom

—step-by-step procedures for achieving specific permanence plans

—case examples

—bibliography (1977, 142 pp)

This volume is available from the Permanent Planning Project, Regional Research Institute for Human Services, Portland State University, PO Box 751, Portland, OR 97207 (no charge).

President's Committee on Mental Retardation. *Programs for the handicapped.* Washington, DC: US Department of Health, Education and Welfare, August 1971.

This report deals with social security programs in the United States, with emphasis on "Childhood Disability" provisions.

Research and Training Center in Mental Retardation. *Information and research materials 1977/78.* Lubbock: Texas Technological University, undated.

The aim of the Research and Training Center in Mental Retardation is to maximize the independence of developmentally disabled people by finding ways to train them in daily living and vocational skills, and by finding ways to improve the service support system. This pamphlet reviews four areas of emphasis in research and training: (1) current research projects, (2) different approaches to training, (3) client service programs, and (4) a variety of resource materials.

Although there is no mention of specific programs for family care of developmentally disabled, support services which could be helpful are listed.

Schaefer, E. S. The family and the education process. Taken from US Department of Health, Education and Welfare, *Current issues in mental retardation and human development.* DHEW Publication No. (OS) 73-86. Elkridge, MD: DHEW, December 1972.

This publication is the result of a special conference on "Mental Retardation and Families." The purpose of the conference was to consider, in depth, a few of the areas where families are involved or affected by the mentally retarded child or adult in their midst. The presentations and discussions ranged across ages and severity of mental retardation, from basic research to current practice, and from education to biomedical factors involved.

The presentation by Earl Schaefer, "The Family and the Educational Process," focused heavily on research verifying the importance of the family in the education of the child. According to Schaefer, the research on family influence on the child's development suggests the need to extend the current classroom perspective on education into a lifetime and lifespace or ecological perspective that recognizes that education begins at birth and ends at death, that everyone is a student and a teacher, and that recognizes the family as the major educational institution (Schaefer, 1971).

Schaefer cites *support* as one influence to the effectiveness of family care and education of children. The support takes the form of social and emotional, as well as financial and material, support. Although support services are being provided, they are fragmented and specialized. Schaefer sees the need to develop family agencies at all levels of government that would focus on the prevention of problems rather than remedial treatment. He sees the need for family agencies to be advocates and organizers; for researchers to find more effective ways of strengthening families; for individuals to develop a national family policy that includes but goes beyond family planning; and for establishment of providers of family programs and family training.

Thurlow, M., Bruininks, R., Williams, S. & Morreau, L. *Deinstitutionalization and residential services: A literature survey.* Project Report No. 1. Information and Technical Assistance Project on Deinstitutionalization. Minneapolis: University of Minnesota, January 1978.

This paper reviews literature on issues related to deinstitutionalization and residential services. The issues have been surveyed in six broad topical areas: a) planning for deinstitutionalization; b) financial considerations; c) individualized program planning and evaluation; d) regulatory issues; e) legal considerations; and f) community services.

Within the review there is specific mention of research concerned with providing incentives and support for in-home family care of the developmentally disabled person.

Turnbull, A. P. & Turnbull, H. R. *Parents speak out: Views from the other side of the two-way mirror.* Columbus: Charles E. Merrill, March 1978.

Parents Speak Out is a collection of personal stories by professionals working with mentally retarded or developmentally disabled individuals. The contributors, who are also parents of handicapped people, focus on the parent-professional relationship and its implications for families, professionals, and the development of programs for handicapped persons.

Designed for a wide range of professionals in education, medicine, law, social work, psychology, human services, and occupational-vocational rehabilitation, the text is useful at both the preservice and inservice level.

The text provides readers with a first-hand account of the problems faced by families of handicapped persons trying to adjust to today's world. In addition, it considers the practical value of such techniques as mainstreaming, deinstitutionalization, and informed consent, while exploring the unexamined effects of these trends in the treatment of handicapped children.

This text is available from the Charles E. Merrill Publishing Company, a Bell & Howell Company, 1300 Alum Creek Drive, Box 508, Columbus, OH 43216.

US Department of Health, Education and Welfare. *Communications and field services. Financial assistance programs for the handicapped.* Washington, DC: Superintendent of Documents, US Government Printing Office, 1968-0-324-554.

This publication is a guide to the department's financial assistance programs for the handicapped. The 68 programs of the Department which relate to handicapped people have been arranged by category as follows:

I. Basic and Supportive Services
II. Research and Demonstrations
III. Construction
IV. Training
V. Income Maintenance
VI. Other

Three types of grants—Formula Grants, Project Grants, and Individual Grants—are also discussed.

In addition, program offices and regional offices of the department are listed as sources of information.

No programs designed specifically to aid in the family care of developmentally disabled individuals were specified. However, support services which could be helpful are listed.

US Department of Health, Education and Welfare. Social & Rehabilitation Service. Respite care for the retarded: An interval of relief for families. Taken from *Residential services for the mentally retarded: An action policy proposal.* The President's Committee on Mental Retardation. Washington, DC: DHEW, 1970.

This publication illustrates services across the United States which are directed primarily toward providing a measure of relief for families of the retarded. The purpose of the study was to focus attention on this major area of deficiency within professional planning for a continuum of care for the retarded. The study illustrates how needs are being met in different community settings. It also focuses on the need for truly comprehensive programs which include a system of supportive services to the family of the retarded.

Vulpe, S. G. *Home care and management of the mentally retarded child.* Toronto, Ontario: National Institute on Mental Retardation of the Canadian Association for the Mentally Retarded, 1969.

This manual describes a behavioral and developmental assessment procedure, treatment techniques, and a method of planning treatment.

Although the focus of the manual is the mentally retarded child, much of the content, theories, treatment techniques, and the assessment procedure itself are applicable to assessment and treatment of preschool atypically developing children

from many diagnostic categories (e.g., physically handicapped, emotionally disturbed, sensory handicap).

Much of the material in the manual is applicable not only to home care, for which it was originally prepared, but to institutional and school settings as well.

Wisconsin Department of Health and Social Services, Division of Mental Hygiene. *Guidelines to community living systems for the developmentally disabled*. Madison, April 1972.

A Community Residential Care Task Force was organized in Wisconsin to formulate basic guidelines for residential care. This document was developed as a guide for the development of future standards, legislation and planning and community programs.

Wolfensberger, W. & Kurtz, R. A. (eds.). *Management of the family of the mentally retarded*. Chicago: Follett Educational Corporation, 1969.

A book of readings on the concept of human management and family management, it was compiled in order to bring together relevant material scattered throughout the literature and over time, facilitating the learning process of family managers.

Specifically, the readings were selected on the basis of four criteria:

1. To present contributions which are likely to enhance practical management competency of persons working with families of the retarded.
2. To acquaint the student or worker with existing writings that present issues, thoughts, or insights so uniquely, succinctly, or incisively that more effective summarization or restatement is not very likely.
3. To bring together sources that have come to be considered classics.
4. To provide a sense of history and continuity.

An effort was made to demonstration: a) the supradisciplinary nature of the management of the family of the mentally retarded and, b) the range and continuity of management options.

Appendix C

Conference Participants

APPENDIX C: LIST OF PARTICIPANTS

This list includes the names and affiliations of persons participating in the Family Care Conference. The function of each individual for purposes of the conference is indicated by a notation at the end of the name:

(P) = Presenter
(C) = Consumer Representative
(R) = Resource Person
(F) = Discussion Facilitator
(A) = Agency Representative
(U) = University of Minnesota Representative

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